University of Alberta

Moving on: Ugandan Families and HIV/AIDS

by

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Abstract

Family coping with the long-term impact of HIV/AIDS, particularly in developing countries, is a growing research area that was previously ignored. To increase our knowledge about the issue, this dissertation investigated how HIV/AIDS-afflicted Ugandan families headed by widows were coping with the devastating impact of this epidemic. Two theoretical assumptions from the life course theory and the stress and coping theory, that families change over time, particularly in response to a crisis, and that families adapt to a crisis' hardships, helped frame this study.

A multiple case study approach was used in this research investigation where interviews and field notes from nine cases were the main data sources. In-depth interviews were conducted with nine educated and employed widows, who gave the researcher access to interview an additional fourteen interviewees representing the widows' children, relatives and friends. Data were analyzed by using a thematic analysis approach across the nine cases, a common strategy used when analyzing multiple-case study data.

The study findings showed that families headed by widows were negatively affected by the long-term impact of HIV/AIDS, particularly when faced with the additional hardships following the husbands' death. These families were also found to employ different strategies to cope with the epidemic's hardships. Three themes summarized this study's findings about the families' experiences with the long-term impact of HIV/AIDS: the changing family structure, the redistribution of family responsibility, and the actions taken to respond to family needs. These themes provided an in-depth understanding of family coping in the context of HIV/AIDS. The studied families were found to (1) experience structural changes involving which relatives stayed in contact with these families and which left the family sphere, and how family support was allocated; (2) reassign family responsibilities and family roles to fill in the empty roles created by the death of the husband; and (3) employ different coping strategies in order to cope with the health and financial demands caused by the HIV/AIDS illness and death, which demonstrated resiliency within these families. Based on these findings, several practical implications of the study are also discussed.

Dedication

This dissertation is dedicated to my beloved father, who allowed me to dare to dream.

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This dissertation is the result of several years of hard work accompanied by the support of many people who made my journey meaningful and fruitful. I take great pleasure in thanking them all.

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CHAPTER 1: INTRODUCTION

In 2007, The Joint United Nations Programme on HIV/AIDS' (UNAIDS) latest report on the epidemic estimated that between 30.6-36.1 million people were living with HIV/AIDS worldwide and that between 1.9 and 2.4 million people had died of AIDS in 2007 (UNAIDS/WHO, 2007). More than eighty percent of these deaths occurred among adults. Developing countries, particularly in sub-Saharan Africa, were most affected, accounting for almost seventy percent of the HIV/AIDS infections and most of the AIDS deaths (UNAIDS/WHO). These alarming statistics clearly indicate that this epidemic continues to represent a huge challenge to individuals, families and communities in sub-Saharan Africa.

For almost three decades since the emergence of the HIV/AIDS epidemic, researchers have tried to understand its full impact on individuals, families and communities. The fatal nature of the disease, particularly for people living in developing countries, initially focused the research agenda on understanding the physical impact of this illness on those infected with HIV and how AIDS-related deaths had affected the demographic structure of the populations in these countries (Timaeus & Jasseh, 2004; Whyte, Whyte, Meinert, & Kyaddondo, 2004; Zaba et al., 2005).

More recently, researchers have begun to turn their attention to studying the impact of HIV/AIDS on families. Family members of HIV-positive individuals have been reported to be physically, emotionally, socially and financially devastated as a result of their heavy involvement in caring for the sick family members (Ainsworth, Beegle, & Koda, 2005; Zaba, Whiteside, & Boerma, 2004). Infected family members often progress to AIDS and eventually die of the illness, setting up a complex family cycle of devastating impacts and related hardships (Barnett & Whiteside, 2002; Manopaiboon et al., 1998).

Understanding this epidemic's effect on families requires understanding both the impact of the hardships caused by this crisis, as well as how families cope with the associated hardships. Interestingly, research on family management of crisis situations related to chronic illness and death has been conducted primarily in the developed world (McCubbin & McCubbin, 1993; Taanila, Syrjälä, Kokkonen, & Järvelin, 2002). The small amount of research from the developing world on family management of a crisis such as HIV/AIDS has documented the devastating impact of this epidemic on the poor in rural areas, who often are left destitute as a result of it (Barnett & Whiteside, 2002).

Moreover, with the recent increased access to antiretroviral drugs (ARVs) for people living with HIV/AIDS (PLWHA) in developing countries, this epidemic is now considered a chronic illness (Lindsey, Hirschfeld, Tlou, & Ncube, 2003). As PLWHA are beginning to live longer, it is expected that they will experience the full magnitude of the impact of HIV/AIDS for several years in the future. Hence, it is important to start investigating how afflicted families are coping with this epidemic's impact in the long run, particularly as more and more PLWHA seem to be able to satisfy their health needs, but to still have to deal with this epidemic's non-health impact. Also, AIDS-related mortality has claimed more male than female lives, leading to the continuing increase in the number of families headed by women, particularly widows (Heuveline, 2004; Madhavan & Schatz, 2007). Few studies have investigated how families headed by surviving widows have been coping with this epidemic's long-tem impact.

The purpose of this study was to address the lack of knowledge on family coping in the context of HIV/AIDS by investigating how Ugandan HIV/AIDS-afflicted families headed by widows have been coping with this epidemic's long-term impact. The study also built on findings from previous research that described a positive correlation between the presence of family resources and a family's ability to cope with crises (McCubbin, 1989). Thus, this research investigation focused on studying the experience of a particular type of HIV/AIDS-afflicted family: those headed by 'resourceful' widows who were educated and employed.

The focus of the study was to explore what the most difficult issues were that these families had to deal with as a result of HIV/AIDS, what strategies the families employed to cope with those difficulties, and what helped these families manage the HIV/AIDS crisis over time, particularly after the death of the husbands/fathers. Conducting this type of research can yield significant information on how HIV/AIDS-afflicted families are coping with the epidemic's long-term and broad impact. Subsequently, this information may inform the design of appropriate interventions for helping these families to sustain themselves.

CHAPTER 2: THEORETICAL FRAMEWORK

The purpose of this study was to enhance understanding of how families change and try to cope with the impact of HIV/AIDS, particularly after losing a family member because of the illness. Theoretical assumptions from the life course theory and the stress and coping theory helped frame this investigation to explore how families were managing their lives following the husbands' death. First, life course theory provided a theoretical understating of family structure and how it changes over time in response to life events. Second, the stress and coping theory provided an understanding of the changes families in crisis may adopt in order to cope, and also of what is known to help these families manage a crisis' consequences.

Thus, to understand the changes within the studied Ugandan families in response to the HIV/AIDS illness and related death, and to develop a better understanding of what strategies these families were employing in order to cope with the HIV/AIDS crisis, the following two theoretical assumptions were used to frame this study:

1. **Families are fluid and dynamic** as they change their structure over time, particularly in response to different life events, including crisis situations (Bengston & Allen, 1993).
2. **Families in crisis adapt** by modifying the families' already established pattern of functioning, using family resources, and experimenting with different coping strategies (McCubbin, Thompson, & McCubbin, 1996).

Assumption I: Families are Fluid and Dynamic Structures

To understand the changes that took place within the studied Ugandan families, a review was needed of how family structure, particularly that of African families, has been theorized. Life course theorists and other researchers have depicted family formulation and composition in normative circumstances as based on and defined by blood linkage and marriages (Bengston & Allen, 1993; Miller & Browning, 2000). According to this definition, two types of families have been recognized by family scholars: the nuclear family and the extended family (Kingsbury & Scanzoni, 1993; Mburugu & Adams, 2005; Wusu & Isiugo-Abanihe, 2006; Ziehl, 2005). African families, including Ugandan families, have often been defined based on these blood and marital linkages (Adams & Trost, 2005; Ankrah, 1993), which made the use of a structural family composition encompassing both the nuclear and the extended family relevant to this study.

Understanding Family Structure

The "nuclear family," also called the "immediate family," often refers to the kin, i.e. family relatives, who have the closest genealogical distance to a person (Adams & Trost, 2005). Accordingly, this type of family consists of the mother, father and the children, who often share the same home (Bengston & Allen, 1993; Eshleman & Wilson, 2001). Other researchers have argued that the nuclear family composition is sometimes more complex and can include other people, who may not be directly blood-related to other family members like adopted children (Madhavan & Schatz, 2007). As well, nuclear families include families of choice where an individual is considered a family member because of personal preference (Johnson, 2000). Thus, these researchers have extended the traditional definition of the "nuclear family."

African families tend to have flexible boundaries, so that other people besides the parents and their offspring are often living within the same 'household.' Some researchers who investigated African households have used the terms "family" and "household" interchangeably, but have also defined a "household" as a group of people who live and eat together on a regular basis (Ansell & Young, 2004; Barnett & Whiteside, 2002; Gregson, Mushati, & Nyamukapa, 2007). In this case, individuals in co-resident households may belong to multiple nuclear families and may include kin from several generations or other people who may not be blood- or marriage-related (Ansell & van Blerk, 2004). This definition deviates from the traditional kinship definition, which describes "kin" as either blood- or marriage-related individuals. In this dissertation, however, the nuclear families included in the study consisted of husbands, wives, and their children.

The "extended family," which is sometimes used synonymously with the "kin-family," consists of the family relatives from both the wife's and the husband's sides (Eshleman & Wilson, 2001). Johnson (2000) explained that kin relationships in extended families are organized according to both lineal/intergenerational and collateral bonds. In the developed and developing world, the "lineal/intergenerational bond" refers to the wives' and husbands' parents' relationship with the nuclear family (Adams & Trost, 2005; Johnson, 2000). The "collateral bond" describes the relationships between siblings, other kin (e.g., cousins) of similar age and nieces and nephews, and between the nuclear family and the in-laws (Eshleman & Wilson, 2001; Singh, 2005). In the current investigation of family coping with the impact of HIV/AIDS, the understanding of these kin relationships helped to clarify the dynamics of family-kin relationships before the families had been affected by the crisis.

Changing Family Structure

Life course theorists and many other researchers have assumed that families are dynamic units liable to structural changes over time in response to normative and non-normative life transitions affecting the families (Bengston & Allen, 1993; Crosnoe & Riegle-Crumb, 2007; Miller & Browning, 2000; Nelson, 2006). Producing and bringing up the children, becoming grandparents, and experiencing aging and death are some of the common normative life transitions affecting families worldwide (Bengston & Allen, 1993; Eshleman & Wilson, 2001).

Non-normative life events, such as the dissolution of families because of family members' separation, also introduce changes into the family structure. Divorce and remarrying are some examples of relationship dissolution and reconfiguration (Johnson, 2000). Socioeconomic factors also influence the nuclear family structure when some adults, often the men, migrate to look for work, leading to fewer members living in the family home (Schafer, 2006).

Another non-normative life event of particular interest to this study is the premature loss of a family member. This situation can lead to significant changes in family structure by creating single-parent families (Bengston & Allen, 1993; Blacker, 2004). The emergence of diseases such as HIV/AIDS has created families headed by widows or widowers, grandparents and children (Ankrah, 1993; Kidman, Petrow, & Heymann, 2007). Families of single-parent mothers/widows were the focus of this study, which explores the impact of family loss on family structure.

The theoretical understanding presented above on family structure was useful in framing the study's findings on how the studied families' structure had changed and how family members had continued to redefine their family boundaries over time in response to the crisis imposed by HIV/AIDS, particularly after the husband's death.

Assumption II: Families in Crisis adapt

Families experiencing crisis situations such as the chronic illness and death of a family member are often faced with significant associated hardships (Bascom & Tolle, 1995; Rosenblatt & Nkosi, 2007; Tak & McCubbin, 2002). According to stress and coping theorists, a family crisis often triggers a family-coping response in order to adapt to the situation (McCubbin & McCubbin, 1993; McCubbin et al., 1996).

Family coping is defined as "the process of managing a stressful life event or situation by the family as a unit with no detrimental effects on any individual in that family" (Boss, 2002, p.79). Boss (2002) further described coping to involve "cognitive, affective, and behavioral process by which individuals and their family system as a whole manage, rather than eradicate, stressful events or situations" (p.79). This study focused on examining the family behavioral responses to the crisis, which represented the active actions taken by family members to manage the hardships caused by the stressful situation. Investigating the tangible coping activities taken by family members was deemed the appropriate approach to follow in this study because it provided a window into the processes by which families recreated their lives and information upon which to determine what other specific actions and activities are needed to help afflicted families better cope.

The current study focused on exploring how HIV/AIDS-afflicted families were coping with the HIV/AIDS crisis. The review of the following three stress and coping theory assumptions that were most relevant to this research investigation was useful in this study. According to these assumptions, a crisis creates new demands on families, requires family members to rethink and reallocate family roles, and makes resources crucial to family coping.

Crises Impose Demands

Crises often present family members with demands that may tax the families' ability to cope (Clark, 2002; Magliano, Fiorillo, De Rosa, Malangone, Maj, & the National Mental Health Project Working Group, 2005). Also, as a crisis escalates, the demands can be expected to increase in intensity and to vary in nature (McCubbin & McCubbin, 1993). The present study used this theoretical understanding to explore the demands imposed on the studied families as a result of HIV/AIDS. The possible physical, social and economic demands associated with this crisis were investigated to learn how these demands had affected the studied families' lives.

The proposition that the escalation in the family crisis affects demands was also considered. In this study, the demands on the families were expected to have increased as they moved from the period of the husband's illness to the period following his death. The family demands imposed by the HIV illness, and particularly those imposed by the husband's death, are explored in detail in this study. This focus was necessary to be able to identify the hardships the families had to endure and to deal with. This understanding provided the starting point for understanding how families adapt to a crisis, which was the purpose of this study.

Rethinking Family Roles

Family theorists describe roles as expected patterns or sets of behaviors associated with a particular position or status of a family member, needed to keep the family going, the family unit functioning, and family members fulfilling their obligations towards one another (LaRossa & Reitzes, 1993). McCubbin and Patterson (1983) hypothesized that in crisis situations, adaptation to a crisis requires the family to introduce changes and modify its already established pattern of functioning to accommodate and respond to the new demands imposed on the family unit by the crisis, so that the family can keep functioning. These required changes and modifications often involve reallocating the roles among family members following the crisis.

In this study, the family roles were expected to have been redistributed among the surviving family members after the husband's death in order to fulfill previous family obligations, as well as new ones resulting from the crisis. The study considered this assumption about the activities and responsibilities assumed by family and non-family members in the HIV/AIDS-afflicted families, particularly after losing the husbands. The vacant role of the family head/family provider as a result of the adult male's death in these families was explored in this study to determine who among the surviving family members or others had stepped in to fulfill this crucial role. This focus was important to understand what roles and how roles are allocated among family members, and what were the most demanding roles that family members had to struggle to fulfill in order to care for their families.

Moreover, McCubbin and Patterson (1983) suggested that the more flexible family members are in adopting new patterns of functioning, which often include the willingness to assume the new roles resulting from a crisis, the more likely these families are to achieve better coping outcomes than families with less flexible members. In this study, the researcher explored how roles were identified and assumed in the nine families and how challenging these roles were to family and non-family members over time. In the current study, considering this concept of the reassigning of roles facilitated the understanding of how the surviving members in the HIV/AIDS-afflicted families identified, assumed and struggled with fulfilling the required roles in order to help their families cope with the illness and the death's repercussions.

Family Resources Matter

Families under stress are expected to use all the resources available to them to manage the crisis's hardships and to respond to the families' needs (Rolland & Walsh, 2006). It is assumed that the presence of *resistance resources*, which are defined as the family's capabilities to address and manage the hardships caused by the crisis, is beneficial to families' ability to adapt to a crisis (McCubbin et al., 1996; Rolland & Walsh, 2006). This understanding informed the current research investigation in that the studied families were expected to use the resources available to them to manage the long-term impact of HIV/AIDS.

Stress and coping theorists classify family resources into the existing and expanded resources that can be present at the individual, family and community levels (McCubbin & Patterson, 1983; Saloviita, Itälinna, & Leinonen, 2003). These theorists define *existing resources* as those that are already part of the family's repertoire, and that can be activated and tapped into immediately after the family experiences a crisis, while *expanded resources* are described as those new resources that family members need to develop and/or acquire to help them manage the hardships associated with the crisis (McCubbin & Patterson, 1983; Tak & McCubbin, 2002).

This theoretical differentiation between resources guided the development of the inclusion criteria for the study participants', mainly the widows'. In this study, the presence of personal resources among the widows, specifically the need to have a certain level of education and to be employed during the time of the interviews, was one of the inclusion criteria. These two personal resources, education and employment, have been theoretically linked to achieving positive family coping outcomes (McCubbin & McCubbin, 1993). Having a reasonable level of education is thought to increase family members' level of knowledge and ability to acquire and process new information and to obtain new resources, which could help these members implement effective coping strategies for their families (Dalstra, Kunst, & Mackenbach, 2006; Liberatos, Link, & Kelsey, 1988).

Moreover, families with employed members are assumed to be able to cope with the crisis's hardships and particularly with its financial burdens (Eriksen, Brown, & Kelly, 2005). Employed family members can meet the families' financial needs that existed before the crisis, as well as respond to new financial needs resulting from the crisis (Lynch & Kaplan, 2000; McCubbin et al., 1996). It has often been argued that having an education facilitates access to employment, particularly to formal employment (Schmidt & Sevak, 2006) in the public and/or private sector. Formal employment can provide the family with a source of income much needed during the time of crisis (Jeffrey, Jeffery, & Jeffery, 2005). Therefore, to be included in this study, the widows were required to have a combination of these two personal resources: education and employment.

Finally, the theoretical assumption of the importance of both existing and expanded resources provided the rationale for the present study to explore the range of personal, familial and societal resources that the interviewed family members had already had, had developed over time, and still needed in order to cope with their family crisis. This information was expected to shed light on the role resources might play in influencing the family coping process and its outcomes.

CHAPTER 3: LITERATURE REVIEW

This chapter presents a critical review of the current state of knowledge on how HIV/AIDS-afflicted families in developing countries, particularly in sub-Saharan Africa, are coping after the illness and death of the husband/father because of AIDS. Following the theoretical framework established in Chapter 2, this review starts by discussing what is known about the structure of African families, how family relations are formed, what family roles are, how roles are allocated among family members, and how resources are distributed in the family. This background information on African families is necessary to understand the social context of the studied HIV/AIDS-afflicted Ugandan families. Research findings on the challenges and changes experienced by HIV/AIDS-afflicted families in developing countries and on how these families manage the difficulties associated with the HIV/AIDS epidemic are also included in this review.

Three databases from the University of Alberta's online library were searched to identify the articles and books used to develop this literature review: the Web of Science, PubMed, and Medline databases. The Google search engine was also used to identify information not found in other databases. The keywords used to conduct the searches were HIV/AIDS; impact; developing countries; Uganda; Kampala; family; women; coping; inheritance; support; ARVs; resources; education; employment. About 650 relevant articles and books were identified from the search, and about 200 of them were used to inform and develop this literature review chapter.

Structure and Characteristics of African Families

The specific structures of African families are influenced by their social and cultural environments and tribal affiliations (Ankrah, 1993; Ziehl, 2005; Gregson et al., 2007). Nuclear families usually include a man, woman and their children (Lansford, Ceballo, Abby, & Stewart, 2001) although polygamous relationships are also common. In these relationships, one man has two or more wives and their children, who may or may not share the same household (Hattori & Dodoo, 2007; Townsend, Madhavan, Tollman, Garenne, & Kahn, 2002). In some countries, like Uganda, the prevalent family structure is patriarchal (Ankrah, 1993; Mburugu & Adams, 2005), so that the family follows the man's blood lineage, particularly in matters involving the wives' and children's family affiliation, and the issue of inheritance (Jankowiak, Sudakov, & Wilreker, 2005). As a result of this cultural structure, a wife and her children belong to her husband's family, and inheritance practices favor the husband's relatives (Ndinda, Chimbwete, Mcgrath, Pool, & Mdp, 2007). This patriarchal system dictates that the men own the land, and that property is passed on lineally to the men's relatives (Adams, 2004). Older sons are eligible to inherit property, and a husband's relatives are likely to inherit as well, particularly if the wife has no children or has daughters only (Mburugu & Adams, 2005).

Furthermore, the practice of having more than one wife, known as polygyny, has been an accepted marital practice in many African cultures (Ankrah, 1993; Tertilt, 2005). However, a large regional variation regarding polygyny exists between West and East Africa. Western African countries have been reported to have a high proportion of polygynous unions, reaching up to 54% in Burkina Faso, in contrast to Eastern Africa where the percentage can be as low as 4%, as in Madagascar (Omariba & Boyle, 2007). In recent years, the practice of polygyny has declined in most African countries (Hattori & Dodoo, 2007), including Uganda (Ankrah, 1993).

One reason for this decline has been the improvement in women's socioeconomic conditions, which has allowed an increasing number of women, particularly in urban areas, to obtain an education (Slonim-Nevo & Krenawi, 2006) and employment (Adams & Trost, 2005). As a result, women's dependency on men as providers has decreased as educated and employed women are able to refuse to share their husbands' emotional and financial resources with other wives (Al-Krenawi & Graham, 2006). In a report using data from the Demographic and Health Survey (DHS) from 22 sub-Saharan African countries, Omariba and Boyle (2007) found that educated women were less likely to enter polygamous relationships and were more likely to work outside of the home than less educated women. However, polygyny is still more prevalent in rural areas than in urban ones in some African countries (Mburugu & Adams, 2005; Ziehl, 2005) because of women's low socioeconomic status in rural areas (Omariba & Boyle, 2007).

Moreover, the gendered division of labor is deeply rooted in traditional African cultures where men and women are assigned specific family roles. Women are expected to be the main caretakers and nurturers of their family members (Mbarika, Payton, Kvasny, & Amadi, 2007; Mburugu & Adams, 2005) by maintaining the home and raising the children (Gibb, Duggan, & Lwin, 1991; Ziehl, 2005). For example, in two early studies conducted in Kenya and in Malawi, Davison (1993) examined views of gender expectations for girls in the two countries and found societal pressure on parents to exclude girls from school and to marry them early, particularly in rural areas. However, in recent years, women's increased access to education has altered this deeply rooted socially prescribed pressure, allowing women to have additional aspirations in life such as seeking employment outside of the home (Mbarika et al., 2007).

The man, who is expected to assume the provider and protector roles in the African family (Ankrah, 1993; Gibb et al., 1991; Adams & Trost, 2005), usually makes the major decisions in the home (Mburugu & Adams, 2005). However, when the husband is away or has died, the wife must assume the decision-making responsibility in the family (Mburugu & Adams, 2005). Onyango, Tucker and Eisemon (1994) examined the relationship between household headship and child nutrition in 154 households in the rural areas of western Kenya by investigating the relationship between decision-making patterns and a family's socioeconomic status. In *de facto* female-headed households, where the husband was away, women had higher levels of education and more cash than women in male-headed households. The first group of women used their money to respond to different family members' needs including those for education and healthcare, and to purchase a wider variety of nutritious food than was usually purchased in male-headed households. The authors found evidence to support the hypothesis that African women who become the heads of their families use the family resources to respond to the important needs in the family to maintain family members' well-being and that these resources often benefit a large number of family members (Barnett & Blaikie, 1992; Mburugu & Adams).

Sharing resources within a kin network is a common practice in African families (Young, 2004) including families in Uganda (Ankrah, 1993). Relatively affluent families, particularly those in urban areas where the employment opportunities are usually better than those in rural areas, were reported to assist their extended families financially on both the man's and the woman's side (Azam & Gubert, 2006). This assistance has been used mainly to support elder kin who can no longer take care of themselves financially, and to support poor siblings and cousins by paying their children's school fees (Adams & Trost, 2005; Ankrah, 1993). A relative's home sometimes becomes the home of children from the extended family when their parents can no longer take care of them because of poverty or the death of one or both parents (Ansell & Young, 2004; Case, Paxson, & Ableidinger, 2004). African families consider children's education to be important, believing that it improves the prospects of the children by increasing their opportunities to access employment in the future (Dass-Brailsford, 2005; Jankowiak et al., 2005).

Further, it is believed that African cities provide supportive settings for improving individuals' financial situations, through either formal employment in the public and private sectors or informal employment through trading (Azam & Gubert, 2006; Rosenblatt & Nkosi, 2007). In its latest report, the International Labor Organization (ILO) indicated that Africans are increasingly moving to urban areas in search of better employment opportunities (International Labor Organization, 2007). However, men earn more money than their female counterparts. Women often have only informal work such as street vending, cross-boarder trading, and/or selling agricultural commodities, while males have more access to formal employment (International Labor Organization). This finding suggests that African women are not favored in the workplace, which seems to be unsupportive of women.

The above discussion of African family characteristics including structures, relationships, and the distribution of resources provided background information on the pattern of functioning within African families and also a context for understating how Ugandan families afflicted by HIV/AIDS manage their lives after experiencing the death of the husband/father because of AIDS.

Identifying the Impact of HIV/AIDS on Families

The majority of the HIV cases and AIDS death occur in the developing world, mainly in sub-Saharan Africa (UNAIDS/WHO, 2006a). Afflicted families in these countries are heavily involved in caring for the sick and in dealing with the long-term social and economic repercussions of illness and death in the family (Baylies, 2002; Chimwaza & Watkins, 2004; Sauerborn et al., 1996). Researchers have come to describe the HIV/AIDS epidemic as a "family burden" (Barnett & Whiteside, 2002; Kidman et al., 2007; Oleke, Blystad, & Rekdal, 2005). In the following sections, the impact of HIV/AIDS on families and how families cope with the impact during two time periods in the family life course are reviewed: the period of the HIV illness of a family member, and the period following the loss of an adult member to AIDS.

Impact of Living with the Illness

After the emergence of HIV/AIDS, researchers started documenting this epidemic's broad impact on families in the developing world (Barnet & Whiteside, 2002; Gibb et al., 1991; Forsythe & Rau, 1998; UNAIDS/WHO, 2006b). For families, the most devastating effects of living with the HIV illness are the health and physical impact on family members, the financial impact of having an HIV-infected person in the family, and the social impact of HIV on afflicted family members' relationships with their surrounding social network and community. These effects are relevant to this study because they provide the starting point for understanding families' experience with the long-term impact of HIV/AIDS, even before an adult's death in the family.

Impact on Family Members' Health

An HIV-positive diagnosis of one family member often signals the presence of an HIV infection in other members (Barnett & Blaikie, 1992; Gupte et al., 2007). In developing countries, the husbands commonly acquire the HIV infection from outside of the home and then transfer HIV to their unsuspecting wives (Ankrah, 1993; Rotheram-Borus, Flannery, Rice, & Lester, 2005; Songwathana, 2001). D'Cruz (2002) studied the impact of HIV/AIDS on families living in Mumbai city in India where she interviewed wives from seven nuclear families. Most of the interviewed HIV-positive wives believed that their husbands had brought HIV home after indulging in extramarital sex, which led to their HIV infection.

HIV/AIDS is particularly devastating for women. According to the UNAIDS report on HIV/AIDS (UNAIDS/WHO, 2006b), women in sub-Saharan Africa account for 59% (13.2 million) of the HIV infections in the region. Women's susceptibility to acquiring HIV has been attributed to their subordinate position in some cultures, which prevents them from negotiating safe sex with their partners (Mathunjwa & Gary, 2006; Miller & Rubin, 2007). As well, the issue of wife inheritance by the deceased husbands' relatives, practiced in some African cultures including that in Uganda (Luginaah, Elkins, Maticka-Tyndale, Landryb, & Mathui, 2005; Oleke et al., 2005), may increase the likelihood of a woman becoming infected with HIV through having sex with HIV-infected relatives from the husband's side (Lugalla et al., 2004; Moore & Williamson, 2003).

Moreover, children born to HIV-positive mothers in the sub-Saharan African region are likely to be HIV-positive and to die of the disease (Harms et al., 2005).

Nakiyingi et al. (2003) conducted a cohort study in the rural area of south-west Uganda between 1989-2000 to determine the contribution of maternal HIV-status to child mortality among children under five years of age. Ten thousand men and women living in fifteen neighboring villages were followed for the duration of the study. The results showed that of the 3727 children born during the study period, 415 had died. Infant mortality risk was found to be more than four times higher for HIV-positive mothers than for HIV-negative ones. The researchers suggested that children died either because of contracting the HIV infection from their mothers or because of the sick HIV mothers' inability to provide proper care for their children. The study concluded that maternal HIV-status was a strong predictor for child survival. These researchers have clearly documented the serious negative health implications of HIV/AIDS on the whole family, including the husbands, wives and children.

Coping with the health impact. Afflicted families cope with the negative health impact of HIV/AIDS on family members by striving to provide the care needed for the sick members (Kalnins, 2006; Mitchell & Linsk, 2004; Demmer, 2006; Harries et al., 2007). Infected husbands often progress to AIDS before their wives do so (Rotheram-Borus et al., 2005), placing the caregiving responsibility on the wives (Joseph & Bhatti, 2004; Kipp, Nkosi, Laing, & Jhangri, 2006; Wight, Aneshensel, Murphy, Miller-Martineza, & Beals, 2006). Wives have a strong obligation to care for their dying husbands. Songwathana (2001) carried out an ethnographic study on the impact of HIV/AIDS on Thai families. Regardless of the wives' HIV status, all wives felt obliged to care for their husbands with AIDS until their death. These wives believed that it was their duty and moral obligation to become their husbands' caregivers because society expected them to do so and because they wanted to avoid feeling guilty for abandoning their husbands when they needed them the most.

Fulfilling the intensive caregiving responsibility required for a patient with AIDS involves helping with a wide range of activities. In a qualitative study conducted with fifteen caregivers of very sick family members with HIV/AIDS in the rural villages of Southern Malawi, Chimwaza and Watkins (2004) found that family caregivers, who were mostly women, took care of feeding, administering both Western and traditional medications, assisting with required physical exercises, fetching, bathing, caring for body sores, carrying the patient to the bathroom, providing emotional and moral support to the sick family member, and maintaining the family home.

Fulfilling these caregiving duties causes emotional, physical, social and economic burdens among family caregivers because of the extensive care involved (Prachakul & Grant, 2003; Thomas, 2006; Nkosi, Kipp, Laing, & Mill, 2006; Vithayachockitikhun, 2006). In a qualitative study conducted with thirty-five family caregivers in three districts in Botswana, some of the burdens experienced by AIDS family caregivers were revealed (Lindsey et al., 2003). The study participants reported feeling overwhelmed by the magnitude, multiplicity and intensity of their caregiving responsibilities towards the family member(s) with AIDS. As a result, these participants became poorer, exhausted, malnourished, and often physically sick because of their neglect of their own health. Child caregivers dropped out of school to be able to attend to their parents' caregiving demands. In addition, all family caregivers in the study mentioned that they felt psychologically distressed and depressed because of the stigma and isolation they were experiencing in their communities as a result of being associated with an AIDS family.

Impact on Family Finances

HIV/AIDS can impose serious economic hardships on afflicted families (Orner, 2006; Sleed, Eccleston, Beecham, Knapp, & Jordan, 2005; Rajaraman, Russell, & Heymann, 2006). HIV/AIDS-induced poverty is caused by the need to provide medical care to a family member with HIV/AIDS, and is aggravated by the loss of the income of the working adults in the family because of the illness and/or the time spent on providing care to the sick member (Forsythe & Rau, 1998; Zaba et al, 2004).

Poverty caused by healthcare costs. Providing medical care to AIDS patients is crucial for prolonging their lives and preventing their health condition from further deteriorating (Jones, 2005; Mitchell & Linsk, 2004; Timmons & Fesko, 2004). The medical costs related to hospitalization and purchasing drugs for a sick family member can be very burdensome (Forsythe & Rau, 1998; Gibb et al., 1991; Zaba et al., 2004). In rural Tanzania, Ngalula, Urassa, Mwaluko, Isingo and Boerma (2002) conducted a study to assess family expenditures on health care services and to determine the impact of medical costs on the families' financial situations. These researchers conducted 197 interviews with individuals who had lost a family member because of AIDS or other illnesses. A large percentage (86%) of the individuals who had died from HIV/AIDS had been ill for at least 3 months. The interviewed relatives reported that their deceased family members with HIV/AIDS had used health services "quite often" and for long durations. People who had died from HIV/AIDS had 1.5 times longer stays in the hospital, 2.2 times more visits to traditional healers, and 3.6 times longer visits to outpatient clinics than people who had died from other causes. The researchers concluded that expenditures on hospital stays were much higher among those who had died from

HIV/AIDS than among those who had died from other causes, resulting in families caring for HIV/AIDS patients having to incur the highest financial burden (Ngalula et al., 2002). This result was attributed to the extensive need of PLWHA for medical care, which had to be purchased by their family members. Because of their families' lack of financial resources, almost half of the family members with HIV/AIDS in the study were not admitted to hospital during the terminal phase (Ngalula et al., 2002).

Even in developing countries with access to free public health care services, HIV/AIDS-afflicted families spend significant amounts of money caring for family members with AIDS. For example, in South Africa, a relatively wealthy African country, public hospitals can be accessed for free. Still, Bachmann and Booysen (2004), in their study on the relationships among HIV/AIDS, incomes and expenditures, reported that among the 202 HIV/AIDS-affected households included in the study, the total health care expenditure was almost two times higher than that in the 202 unaffected households included in the study. The increased costs in the HIV/AIDS-afflicted households were attributed to the transportation costs for repeated visits to the hospital and for the purchase of the drugs needed for the sick family member (Bachmann & Booysen, 2004).

ARV medications, important in treating AIDS, may be unattainable for infected family members in many developing countries because the cost may push these families into poverty (UNAIDS/WHO, 2006b). Some developing countries provide free access to ARVs (Bartlett & Muro, 2007; Chien, 2007); however, millions of HIV and AIDS patients in these counties still do not have access to this free service (Wilson & Blower, 2005; UNAIDS/WHO, 2006a). In Chad, one of the poorest countries in the developing world, Wyss, Hutton and N'Diekhor (2004) studied the impact on families of the cost of purchasing AIDS drugs and traditional remedies, paying for medical consultation fees, laboratory investigations, and diagnosis and hospitalization, and obtaining transportation to seek medical care. The researchers interviewed 193 AIDS patients and the same number of non-AIDS patients. The average out-of pocket expenditure incurred by the AIDS patients and their families per month was more than twenty-one times the medical costs incurred by the non-AIDS group. All the health costs reported in the study were paid for directly by family members of the HIV individual.

Poverty caused by lost income. HIV/AIDS also can affect family finances by affecting the family's ability to generate income. The disease is prevalent among economically active young people, whose labor force participation is reduced or prevented as a result of the illness (Bloom, Rosenfield, & Path, 2000; Zaba et al., 2004). The disease also affects caregivers' employment, for they have difficulty managing their work demands while providing the intensive caregiving needed by an AIDS-family member (UNAIDS, 2000; Danziger, 1994).

To determine the impact of losing income on an HIV/AIDS-afflicted family, Rajaraman et al. (2006) examined the mechanisms through which working adults lost income in HIV/AIDS-afflicted families in Botswana between 2000 and 2001. In this study, 254 in-depth interviews were conducted with adults who were attending government health clinics and who were caring for at least one HIV-infected child or adult. The authors found that the income loss in the families of working adults resulted from unpaid leave for twenty-one percent of the caregivers of children and for eighteen percent of the caregivers of adult family members. Caregiver respondents with HIV symptoms also experienced income loss as a result of being frequently sick and unable to work, and sometimes losing their jobs.

Coping with the financial impact. Families experiencing a financial crisis will try to manage and cope by using several strategies. In an early study, Sauerborn et al. (1996) examined how families in Burkina Faso were coping with the economic impact of HIV/AIDS. Using data from 51 interviews carried out in two villages, these researchers found that the families first used their savings to manage the increasing costs of health expenditures. When these resources proved insufficient, the families sold assets such as livestock and land. A third strategy was to borrow money or take a loan or accept gifts from extended family members. However, the latter option was available only to wealthy families who either had assets such as animals and land to guarantee the repayment of a loan, or were believed to have the potential to reciprocate favors and gifts in the future. Developing an income-generating activity was another strategy used by some families. Sauerborn et al. (1996) found that such activities included fetching firewood for millet beer breweries, building fences, weaving straw mats, making honeycombs, and tailoring.

HIV/AIDS-afflicted families also prioritize their spending to respond to the most urgent family needs. In a study on the economic impact of HIV/AIDS on families in Chad, Wyss et al. (2004) reported that the study families allocated almost half of their income to respond to the healthcare needs of an AIDS-member. As a result, these families spent less money on food and even less on clothing. In contrast, non-AIDS-families spent most of the family income on food, health, and clothing, in that order. The researchers concluded that afflicted families needed to experiment with different coping tactics to manage financially.

Impact on Social Relationships

Societal beliefs about the mode of HIV transmission, the deadly nature of the disease, and people's fear of being burdened by the costs associated with providing support to afflicted individuals and their families can result in the isolation and stigmatization of families, and in discrimination against them (Barnett & Whiteside, 2002; Moore & Williamson, 2003). In a study in India, Joseph and Bhatti (2004) explored the social and psychological impact of HIV/AIDS on the families of thirty HIV-positive women. Generally, the transmission of HIV has been linked to immoral behavior and promiscuity. As a result, the majority of the interviewed women indicated that they and their family members felt abandoned by most people they knew, including their own relatives, neighbors, and friends (Joseph & Bhatti, 2004). The families in the study were also excluded from family gatherings and social functions because people feared acquiring the HIV infection and dying of the disease.

Sometimes, community groups, including religious institutions, isolate the families afflicted by HIV/AIDS. In a study of the impact of caring for an AIDS relative on family caregivers in KwaZulu-Natal, South Africa, Demmer (2006) reported that Churches condemned people for their inappropriate sexual behavior, perceiving their infection as a punishment from God. The cost associated with providing support to HIV/AIDS-afflicted families also leads to family isolation. Moore and Williamson (2003) studied the impact of HIV/AID in Togo in West Africa, interviewing thirteen health care professionals and seventeen non-health care professionals who worked with PLWHA. The researchers reported that the costs associated with managing the impact of HIV/AIDS, and the likelihood that poverty in afflicted families would preclude repayment of loans and exchange of favors in the future, discouraged some relatives from sharing the little money they had for their own families. For this reason, these relatives disassociated themselves from their HIV/AIDS-afflicted relatives, contributing to their further social isolation (Moore & Williamson, 2003).

Coping with isolation. The strategies that family members adopt to cope with social isolation include denying the situation and garnishing support from others in the afflicted family's social network. Joseph and Bhatti (2004) found that their study participants concealed their HIV-positive status from other people, including family members, and sometimes chose deliberately to isolate themselves and their families from their social environment.

Although being affected by HIV/AIDS can lead to discrimination from relatives, some relatives support afflicted families. In a study in Yunnan province (China), Li et al. (2006) found that support was linked to improvements in the afflicted family members' quality of life. In the thirty interviews conducted with PLWHA, the interviewees indicated that relatives had provided a wide range of support including financial and emotional support. Therefore, the PLWHA in the study did not suffer social isolation, but became motivated to take care of their health and acquired a positive outlook on life despite their illness.

Impact of Family Loss on Family Life

Loss of an adult male in the family, particularly the husband/father, results in changes in family composition and structure, and household size (Heuveline, 2004; Zaba et al., 2004) and can also result in loss of the family's protector and income earner

(Nyamukapa & Gregson, 2005; Wyss et al., 2004). These effects and the current knowledge of how families deal with them are discussed below.

Changes in Family Composition and Structure, and Household Size

Family composition and household size may experience changes beyond the loss of a member because of HIV/AIDS. An adult death because of AIDS may lead to an additional reduction in household size when the surviving parent sends his or her children to relatives (Foster, 2007; Heuveline, 2004). Household size may also increase after the death of family members because of the illness. In a study conducted between 1997 and 2000 in rural areas in Kenya with high HIV infection rates, Yamano and Jayne (2004) reported that a significant number of new members had been added to the 1,422 households included in the study. The households with new members were extended family households that had adopted children whose mothers had experienced severe hardships after the AIDS-related deaths of their husbands. This finding also suggests a possible reduction in the size of the widows' households because of their children moving to other extended family households.

HIV/AIDS-afflicted households sometimes provide refuge to other relatives affected by HIV/AIDS, again increasing the household size. In a recent study conducted among the Zulu of South Africa, Rosenblatt and Nkosi (2007) found that the studied households' size increased when some extended family members began living in households headed by widows. In this study, fifteen of the sixteen interviewed widows indicated that they had other people living with them besides their biological children. These additional members were mainly the grandchildren, nieces and nephews of relatives who were dying or already dead because of HIV/AIDS. The need for laborers is another reason for bringing additional individuals into a household. Yamano and Jayne (2004) found that in rural Kenya, households that had lost a working adult male as a result of AIDS compensated by bringing boys from the extended family into the household to do the work needed on the farm.

Loss of the Parent and Family Protector

The loss of the husband in a family often means the loss of the father (Ankrah, 1993; Case et al., 2004) and of the family's protector and defender (Rosenblatt & Nkosi, 2007). Following the husbands' death, some African widows have difficulty disciplining their children alone (Rosenblatt & Nkosi). Data from focus group discussions with widows conducted in Nyanza, Kenya, indicated that the most common challenge the widows faced was taking care of their children in the absence of the children's fathers (Luginaah et al., 2005). The widows in Luginaah et al.'s (2005) study expressed fear and anxiety about being single parents and taking on all the responsibilities which come with this status. Some widows also noticed anxiety and stress among their children, who worried about losing their mothers as well.

Moreover, in some African cultures, like those in Nigeria, Kenya, and South Africa, adult males are viewed as the family protectors who defend the wives and the children against others, including relatives (Adams & Trost, 2005; Rosenblatt & Nkosi, 2007). Therefore, the death of the adult male in a family has been associated with widows losing their social respect and becoming vulnerable to abuse (Joseph & Bhatti, 2004). In-laws in particular are a source of trouble for many African widows, who, after their husbands die, sometimes lose not only their claim to the family property but also their in-laws' support (Adam & Trost, 2005; Cattel, 2003).

Furthermore, legal measures seem to do little to protect widows and their children from being disinherited. Mendenhall et al. (2007) analyzed 184 wills written mainly by HIV-positive men in Lusaka, Zambia and reported that the majority of the HIV-positive males wanted to leave most of their possessions to their wives and children. However, these men appeared to doubt that their relatives would respect the wills' stipulations pertaining to the distribution of property. Thus, many wills had clauses indicating that the relatives should be prevented from taking the men's property (Mendenhall et al., 2007). For example, to try to prevent his relatives from seizing his property after his death, one man wrote in his will, "When I die I don't want anyone to tamper with my property; it's for my wife and children" (p. 372).

Roys (1995) identified reasons why some Ugandan widows were unable to prevent their inheritance from being seized by their in-laws. One problem was that, in the mid-1990s, the practice of will writing was new in Uganda. Given the high illiteracy rate among women and their lack of autonomy, widows were unable to ensure entitlement to their deceased husbands' property even if they had a written will. Recently, Mendenhall et al. (2007) reported similar findings in a study in Zambia of the significance of will-writing in protecting HIV/AIDS-afflicted families' property inheritance. The study findings indicated that although Zambian statutory laws recognize a written will and the women and children's right to inheritance, few women in the country were knowledgeable about their legal rights under the law. Therefore, the widows were often unable to claim their deceased husbands' property and to protect their family's financial resources from their in-laws.

Financial Impact of Family Loss

After the AIDS-related death of the husband, the depletion of the family's financial resources continues (Hosegood, Preston-Whyte, Busza, Moitse, & Timaeus, 2007) as a result of the loss of the family's inheritance and the reduction in family income caused by the loss of an income earner (Barnett & Whiteside, 2002). Property loss usually occurs immediately after the husband's funeral, when the in-laws take whatever is left of the family's possessions, leaving already poor widows and their children in economic distress (Mendenhall et al., 2007). This impact is acute during the period immediately following the husband's death, when the surviving family members have not yet developed a plan to generate the income needed for survival (Luginaah et al., 2005; Ankrah, 1993).

A reduction in family income also results from the permanent loss of the deceased husband's financial contribution (Gregson et al., 2007) and, sometimes, from the reduction in the surviving family members' ability to contribute financially (Danziger, 1994). In a quantitative study carried out in rural Kenya, Zaba et al. (2004) reported that the death of an AIDS male household head was associated with a 68% reduction in the net value of the household's crop production. Also, since men who die of AIDS are relatively young, financial losses can affect their families over a long period of time. For example, Konde-Lule & Sebina (1993) found that in rural areas of Kasangati, Uganda, the average age of male adults who had died from AIDS was 30 years compared to 47 years for those adults who had died of all other causes, resulting in the AIDS victims' loss of 17 productive years.

Families in urban areas experience similar economic losses. In Zimbabwe, Gregson et al. (2007) found that loss of jobs among adult members because of death was sending HIV/AIDS-afflicted households in urban and rural areas into deeper poverty. Mortality was measured among the 9842 adults interviewed in this study, who were followed for three years. At the end of the study, 125 men and 163 women had died of AIDS. Loss of paid employment was the main reason for reduced income in the deceased adults' households, particularly in households where the deceased had been the head of the family.

Surviving adults may suffer employment discrimination, making it difficult for employees from HIV/AIDS-afflicted families to be employed or to keep their jobs. Although measuring this type of impact on the families' economic well-being has been challenging, researchers have linked workplace discrimination and family poverty. Danziger (1994) and Ankrah (1993) suggested in their literature reviews that individuals coming from known HIV/AIDS-afflicted families in developing countries, including Uganda, may be unemployable. Business owners tend to dismiss employees from families with a history of HIV/AIDS (Danziger, 1994; Forsythe & Bill, 1998). Rajaraman et al. (2006), in a study of single mothers in Botswana, reported that half of the single mothers who used to be employed had lost pay because of either their physical inability to work or their need to stay at home to care for sick family members, particularly children. The researchers suggested that employers were concerned that HIV-positive employees could create increased business costs because sick workers can be expected to be absent from work more often than healthy ones, and frequent absenteeism reduces workplace productivity. Another reason mentioned for workplace discrimination has been that sick employees may be eligible for medical care, widows' or widower's pensions, and/or other welfare provisions and benefits that employers consider too costly to incur (Uganda HIV/AIDS Manual for Workplaces, 2004; Weston, Churchyard, Mametja, McIntyre, & Randera, 2007). Employers also might fear that if they employ infected individuals, the HIV infection will spread among other co-workers, further decreasing workplace productivity (Danziger, 1994). In general, HIV-positive adults have an increased likelihood of becoming unemployable in either formal or informal sectors (Danziger, 1994; Forsythe & Rau, 1998) and thus of being unable to provide a secure source of income for their families (Kiereini, 1990).

Family Coping with the Long-term Impact of HIV/AIDS

The current evidence, although limited, suggests that HIV/AIDS-afflicted families have been resilient in responding to the epidemic (Foster, 2007; Mutangadura, Mukurazita, & Jackson, 1999) and that these families are capable of recovering from some of its impact as time passes (Barnett & Whiteside, 2002; Kanyamurwa & Ampek, 2007; Ansell & van Blerk, 2004; Mutangadura et al., 1999). The family coping approaches applied so far include staying alive for the sake of the family and managing the family's financial needs.

Focusing on Staying Alive for the Family

Family reasons have been found to motivate PLWHA to fight for their lives by seeking treatment. For instance, HIV-positive mothers have often been reported to fear for their children's future and to worry about who will take care of the children when the mothers die of AIDS (Gibb et al., 1991; Manopaiboon et al., 1998). In a descriptive qualitative study conducted in Eastern Uganda on the experience of seven HIV/AIDS-positive women who were all mothers, Withell (2000) highlighted the mothers' fear. These women stated that they were fearful for the future of their children, particularly if they (the mothers) died (Withell, 2000).

In recent years, the desire to live for a few more years has been found to motivate many HIV-positive people, including women in developing countries, to seek medical treatment (UNAIDS/WHO, 2006a) in order to continue to care for their families, particularly the children. For example, in one study, the researchers reported their findings from in-depth interviews with ten Ugandan PLWHA in Kampala, mostly women, who were buying ARVs either with their own money, or sometimes with the assistance of some relatives (Crane et al., 2006). The results showed that the majority of the study participants had an intense desire to continue to take their medication so that they could stay alive to take care of their children and other family dependents (Crane et al.).

PLWHA may want to respond to their urgent health needs, but financial constraints and the expense of ARV therapy have been listed as barriers for many PLWHA trying to access treatment in developing countries (Holmes, Bilker, Wang, Chapman, & Gross, 2007; Vasan et al., 2006; Wolfe et al., 2006). For example, in 2006 in Uganda, 34% of the PLWHA who were eligible for treatment were not receiving it (UNAIDS/WHO, 2006a). The cost of the medication has repeatedly been mentioned as the main reason for this situation in Uganda (e.g., Crane et al., 2006). Crane et al. (2006) reported that, in spite of the programs providing free access to ARVs in Uganda, many PLWHA in this country were still spending almost half of their monthly income (about US$27) to purchase ARVs on a monthly or twice-monthly basis.

Managing Family Finances

Families in the developing world have been adopting a number of coping strategies to manage the economic hardships associated with an adult's death because of AIDS. These strategies include preserving and using the already existing assets in the family, reducing family expenses, and bringing in more financial resources to the family by working and acquiring material support from external sources (Barnett & Blaikie, 1992; Mutangadura et al., 1999; Yamano & Jayne, 2004).

Using family assets. Research cited earlier in this review showed that HIV/AIDS-afflicted families depleted most of their financial resources while caring for the sick adult family member, and that a widow was at risk of losing her property to her in-laws following her husband's death. Little research has been carried out on the impact of these financial losses on widows and their children and on their strategies to keep and use their financial assets. Some evidence, however, suggests that after the death of the husband/father, families first exploit the resources they possess in order to respond to the families' basic needs for food, shelter, treatment for sick family members, and children's education (Mutangadura et al., 1999; Loewenson, 2007; Nyamukapa & Gregson, 2005). The use of this strategy was documented in Kanyamurwa and Ampek's (2007) study of one hundred randomly selected HIV/AIDS-afflicted households and one hundred randomly selected non-HIV/AIDS-afflicted households in rural Uganda. The AIDS-afflicted households were likely to rent their land to generate income. In some AIDS-afflicted households, widows were able to cultivate some of their land for food. The land was often sold later. Female-headed households affected by AIDS, which were the poorest, were more likely than other households to have sold household items such as furniture, radio and bicycles and livestock to generate income.

Some researchers have reported that the financial relief that comes from selling assets is only temporary (Barnett & Blaikie, 1992; Mutangadura et al., 1999), particularly for households headed by women (Kanyamurwa & Ampek, 2007). The depletion of a family's financial resources may leave a household in a dire situation by accelerating its slide into deeper poverty and reducing the household's ability to cope with the long-term impact of HIV/AIDS (Moore & Williamson, 2003).

Reducing family expenses. Another strategy used to manage family finances is to reduce the family's financial expenses by, for example, shifting the cost of caring for the children to other family members (Kidman et al., 2007). Ansell and van Blerk (2004) studied children's movements between different households in four communities in Lesotho and Malawi as a method of family coping with the financial impact of HIV/AIDS. These researchers found that some extended families, particularly the maternal relatives, were willing to absorb children into their homes. These relatives incurred the cost of sheltering, feeding, clothing, treating and educating the children. This kind of support relieves some of the financial burden on the HIV/AIDS-afflicted parents by reducing their families' costs of living. However, such extended family support systems are fragile (Ansell & van Blerk, 2004; Rosenblatt & Nkosi, 2007). Kidman et al. (2007), in their literature review on the crisis of orphans in Africa, noted this reality. These researchers reported that extended family members were finding it increasingly difficult to provide the proper care for children from HIV/AIDS-afflicted families.

Another strategy used to reduce family expenses is to skip payments of recurrent family costs, such as children's school fees. Case et al. (2004) examined 19 Demographic Health Survey (DHS) datasets from 1992 to 2000 for ten sub-Saharan African countries, including Uganda, where HIV/AIDS was prevalent. The researchers estimated the school enrollment in the region among children who had lost a father or mother and those who had two living parents. The researchers found that the children who had lost a parent, either a mother or father, had significantly lower school enrollment than non-orphaned children. Lower school enrollment was most likely in households that had lost the father, who was often the family's main income earner (Case et al., 2004). The significant income decrease in households headed by mothers, which the researchers considered to be the poorest households, and the expenses attached to educating the children, such as paying for school fees, school supplies, and school uniforms, were the reasons for the decrease in children's enrollment in school (Case et al.). These families needed to reduce their expenses by forgoing their children's education in order to respond to other family demands, mainly for food, which were perceived to be more important.

Bringing in money for the family. Another coping strategy used by family members to respond to their financial needs is to pursue different ways to generate income from formal and/or informal employment. The death of the family breadwinner has been described as a major motivator for surviving family members to look for work to increase their family income (Rajaraman et al., 2006). Seeking formal employment in the public and/or private sectors is one approach to responding to families' financial needs (Brooks, Martin, Ortiz, & Veniegas, 2004; Hergenrather, Rhodes, & Clark, 2005). Research evidence from the developed world sheds light on why PLWHA want to reenter the labor force. In Washington, DC, Hergenrather et al. (2005) conducted focus-group discussions with 54 African-American PLWHA, most of whom were unemployed. The researchers explored the factors influencing job-seeking behaviors among these PLWHA. Most of the participants mentioned that their need for money was the main reason why they wanted to join the work force. The participants wanted to become self-sufficient economically and to be able to provide for their families. Interestingly, most of the research on employment in the context of HIV/AIDS has been carried out in the developed world (Braveman, Levin, Kielhofner, & Finlayson, 2006; Brooks et al., 2004; Hergenrather et al., 2005). Very little research on the issue of employment of PLWHA in the developing world has been published.

Obtaining formal employment requires a person to have personal resources such as education and professional skills (Larsen & Hollos, 2003; Yamokoski & Keister, 2006). However, many African women have poor educations and lack desirable market skills and training (Moore & Williamson, 2003; UNICEF, 2007). Therefore, these women often cannot compete in the labor market to secure formal jobs (Moore & Williamson, 2003; UNICEF, 2007). Ramachandrana, Shahb, & Turner (2007) analyzed data from the World Bank Enterprise Survey for Uganda, Kenya and Tanzania, which encompassed 860 firms in the manufacturing sector offering formal employment in these countries. In this survey, 4950 workers (80% men and 20% women) in the three countries were interviewed. The highly educated workers, who represented the lowest percentage, had the best jobs with the highest salaries. Unskilled workers with poor educations occupied the lowest positions and made the least money. The researchers concluded that the higher the education and skills of an individual, the more likely he or she was to land a high-paying job in the formal sector. As well, women were less likely to be employed in the formal sector than men because of their lack of adequate levels of education and training.

Seeking informal employment. The lack of education and professional skills has forced many workers in the developing world to work in the informal sector, which provides them with their main source of income (Le Marcis & Ebrahim-Vally, 2005; Martin, Wolters, Klaas, Perez, & Wood, 2004). Songwathana (2001), for example, studied families' experience with HIV/AIDS in Bangkok, Thailand. The fifteen women included in the study reflected on their families' experiences with HIV/AIDS from the time of their partners' illness until after his death. Five husbands in the study were reported to have died of AIDS and left wives and children behind. The wives who became widows had to become the main contributors to their household income. The widows said they took on informal work, which involved the door-to-door selling of goods and doing housework for other families. Some widows had to take on more than one informal job in order to earn enough income to compensate for the deceased husbands' lost income.

Starting a private business can be another way of bringing in income for the family, but it requires financial capital to get started. Researchers have suggested that in Africa, borrowing money and obtaining loans and credit from external sources, mainly community groups and organizations, provide the main sources for acquiring this capital (Le Marcis & Ebrahim-Vally, 2005; Sherer, Bronson, Teter, & Wykoff, 2004). Community financial support in the form of loans and microcredit has been described as helpful to individuals and their families in their efforts to manage their finances

(Mutangadura et al., 1999; Sherer et al., 2004; UNAIDS, 2004). However, Mutangadura et al. (1999) reported that the high interest rates associated with most of these loans were preventing many HIV/AIDS-afflicted families in developing countries from accessing the type of financial support needed to start a private business.

Summary of the Review

This review showed that HIV/AIDS has a long-term devastating impact on families, which goes beyond experiencing the physical illness and death of a family member with AIDS. The gradual increase in access to ARVs in many developing countries has increased AIDS-afflicted families' ability to cope with the physical impact of the illness leading to an increase in the number of PLWHA surviving the illness and live to experience its long-term impact for many years to come.

This review shed light on the situation of poor HIV/AIDS-afflicted families in the rural areas of some developing countries, but the situation of the middle-class families who are also affected by this epidemic is still not well understood. The full magnitude of this epidemic on all families of all social classes must be clarified in order to design appropriate interventions for addressing the specific needs of each group of families. Understanding the epidemic's impact and the coping process of HIV/AIDS-afflicted families headed by widows, which are often viewed as the most vulnerable families, is particularly important since the number of these families has gradually increased in many developing countries. This understanding is needed to identify appropriate strategies for assisting these widows and their children to cope with the loss of their husbands and fathers.

Thus, this study was designed to investigate the experience of HIV/AIDS-afflicted families headed by widows who were caring for their biological children. Specifically, in order to determine how HIV/AIDS-afflicted families in the city of Kampala, Uganda, who were headed by educated and employed widows, were coping with the long-term effects of the HIV/AIDS epidemic, this study's purpose was to investigate the coping experience of nine of these families.

CHAPTER 4: METHODOLOGY

In this chapter, relevant methodological issues are discussed: the rationale for using a case study methodology, the Ugandan context, the sources of data, sampling procedures, data-collection methods, and the data-analysis plan used to identify the study's findings.

Rationale for Using the Case Study Methodology

Several factors made the use of the case study methodology appropriate for this investigation. This methodology is often used to capture detailed in-depth information on the research area of interest, particularly when little is known about the investigated topic (Anderson, Crabtree, Steele, & McDaniel, 2005; Creswell, 1998). The case study methodology pays special attention to the importance of context in reaching an accurate representation and interpretation of research findings (Yin, 1994). The context where the studied families were situated was of particular relevance. As mentioned in Chapter 2, family coping with crisis has been described mainly from the perspectives of the developed world. In this study, Uganda, a developing African country, was selected as the place for conducting this investigation, so that the use of a research methodology that encourages understanding of the context was appropriate.

The case study approach enables the researcher to be immersed in the research setting while learning about the people's behavior, cultural and traditional values, and to enhance understanding of the issue under investigation (Yin, 1989). In this study, being engaged in the field for almost eight months enabled the researcher to gather additional valuable information on the situation of HIV/AIDS in Uganda through the media, communicating with other people in addition to the research participants, and visiting different organizations involved in working with PLWHA. Thus, the researcher was able to collect supplementary information and to understand some of the important facts about the political and cultural context in the country that were influencing how HIV/AIDS is affecting Ugandans.

Moreover, the case study methodology permits the theoretical framing of the research (Anderson, et al., 2005; Creswell, 1998; Yin, 2003a). Specific assumptions from the life course theory and the stress and coping theory were used to develop this study's conceptual framework, and these assumptions informed the study's data collection, analysis, and the reporting on the study findings.

The case study approach encourages the use of multiple data sources to gather information on the studied phenomenon (Yin, 2003b). Stake (1995) argued that this characteristic helps to enrich the collected data, to confirm the study's results, and to validate its findings. Thus, the current study used multiple data sources, interviews and field notes. For all the above reasons, the case study methodology was chosen to guide this investigation.

The Multiple Case Study Approach

A case study methodology can follow one of two approaches: single-case and multiple-case study. A single case study approach is often used when studying a unique or rare case, and when the same case is studied over different points in time (Yin, 2003b). The families included in this study did not satisfy this criterion because thousands of families are afflicted by HIV/AIDS around the world (UNAIDS, 2004). As well, the study's purpose was not to conduct a follow-up research investigation on understating the situation of these families over a period of time in the future, but to learn about the families' coping experience with the impact of HIV/AIDS from the time of the husbands' death up to the time of the conducting of the interviews. The multiple-case study approach was more suitable for this investigation because of this approach's distinct advantage of permitting the researcher to study several cases at the same time, and to study people who have experienced the same phenomenon (Yin, 2003b).

Findings from a multiple case study can be considered compelling if they reveal similar patterns across cases (Stake, 1995; Yin, 2003a). For these reasons, a multiple-case study design was used in this study to identify patterns across cases, to highlight the range of strategies used in all the families to manage the impact of HIV/AIDS, and to illustrate the long-term hardships faced by these families.

To conduct this multiple-case study, these main steps were followed as recommended by Patton (2002), Stake (1995) and Yin (2003a): understanding the context of the study; defining what is the "case"; identifying data sources; developing a data-collection plan to access the population of interest; and developing a plan for the cross-case analysis.

Study Site

Uganda was selected as the country for conducting this study because of this country's long history with the HIV/AIDS epidemic and with combating its impact. The following paragraphs provide a description of the country and of its history with the HIV/AIDS epidemic.

Uganda is located in East of Africa across the equator with a total area of 236,040 square kilometers (see Appendix F and Appendix G). The country borders the Democratic Republic of the Congo (DRC) on the west, Sudan on the north, Kenya on the east, and Tanzania and Rwanda on the south (WHO/AFRO, 2001). In 2005, Uganda's population was 28,816,000 with an annual growth rate of 3.4% (WHO, 2006).

The literacy rate is 66.5% of the total population (UNDP, 2007). Adult literacy is 74% for men and 50% for women (Vavrus & Larsen, 2003). The languages spoken in the country are English, which is the official language, and Swahili, Bantu and Nilotic languages. The majority of the population is Christian, but 16% of Ugandans are Muslims, and 18% have indigenous beliefs. The fertility rate is 6.7 children per woman, and life expectancy at birth is 48 years for males and 51 years for females (UNAIDS, 2007). In the 15-60-year-old age group, the death rate is about 506 per 1000 for males and 457 for females (WHO).

Uganda is one of the poorest countries in sub-Saharan Africa; 90% of the population lives in rural areas, and the country's economy depends on agriculture (UNAIDS, 2004). In 2003, the per capita government expenditure on health was 23 dollars (WHO, 2006). Although no data are available on Uganda's unemployment rate, it is expected to be high, particularly in the rural areas and among women.

Kampala City

Kampala (see Appendix G), the location were the study was conducted, is Uganda's capital and largest city and is located in the district of Kampala. Recent estimates are that Kampala's population is 1,208,544 (Wikipedia, 2008). The city is the location of the county's government offices and main hotels, banks and shopping malls. The best educational institutions in the country are in Kampala, which is also home to Makerere University, one of East and Central Africa's premier institutes of higher learning (Wikipedia). Kampala is also home to the biggest teaching hospital in the country, Mulago Hospital, and to other big hospitals such as Nsambya Hospital (Wikipedia). The city has a relatively good infra-structure, particularly when compared to other cities in the country and to the rural areas. Some parts of the city have access to water and electricity. Kampala hosts several national and international organizations working with PLWHA such as The Uganda AIDS Commission (UAC), The AIDS Support Organization (TASO), The Forum for PLWHA Network, the European Union (EU) country offices, and several United Nations country offices such as the WHO, UNICEF, UNDP and the Global Fund.

HIV/AIDS in Uganda

HIV/AIDS was first observed in Uganda in 1982 along the shores of Lake Victoria in the Rakai district in Southern Uganda (Kaleeba, Kadowe, Kalinaki, & Williams, 2000). The Ugandan civil war and its aftermath of poverty, malnourishment, and collapsed health services provided an environment conducive to the spread of HIV. By the beginning of 1990, Uganda had become the epi-center for the HIV/AIDS epidemic in Africa (Barnett & Whiteside, 2002; Human Rights Watch, 2003). By 2001, over 2 million Ugandans had been infected with HIV, and about 900,000 had died since the onset of the epidemic in the country (Kanyamurwa & Ampek, 2007). Eighty percent of those infected were between 15 and 45 years of age and represented the most economically productive and reproductive group of the population (UNAIDS, 2004). It has been estimated that the total deaths due to HIV/AIDS in the year 2003 ranged between 54,000 and 120,000 among both adults and children, making AIDS one of the main leading causes of death among the adult and child populations in Uganda (UNAIDS).

The high rates of AIDS-related deaths have resulted in the emergence of a new family type in which women who are either single, widows, or grandmothers are the predominant heads of HIV/AIDS-afflicted households and families (UNAIDS, 2004). According to the same UNAIDS report, Uganda has an orphan population of more than two million, and half of this population are AIDS orphans (UNAIDS). These alarming statistics indicate that HIV/AIDS continues to represent a real threat to Uganda's stability and its present and future social and economic development.

Early in the epidemic, the government in Uganda adopted an open approach of declaring and acknowledging the presence of the problem and lobbying for assistance to combat the HIV/AIDS epidemic (The Uganda AIDS Commission, 2004). This approach has proven to be constructive and effective (Moore & Williamson, 2003), resulting in a steady decline of the HIV prevalence from the peak of 29.4% in 1992 (Human Rights Watch, 2003) to 6.7% in 2005 (UNAIDS/WHO, 2007). This achievement was also the result of the success of the implemented national HIV/AIDS prevention and control programs, and the involvement of civil society, religious institutions, and communities along with the government in dealing with this epidemic (Kanyamurwa & Ampek, 2007). Hence, Uganda has become a beacon of hope and a success story in sub-Saharan Africa in the area of preventing and controlling the spread of HIV (UNAIDS, 2004). Moreover, in recent years, through the financial support of the US President's Emergency Plan for AIDS Relief (PEPFAR) and of the Global Fund (Cohen, 2005; Alliance for Health Policy and Systems Research /WHO, 2004), ARV coverage in Uganda in 2005 was estimated at 51% of all people in need of treatment (WHO, 2006). This estimate suggests that 49% of HIV-positive Ugandans in need of treatment are still not receiving it.

Achieving even such limited success has been a long and painful process for Uganda, but this country is now able to embark on new initiatives dealing with other equally important impacts of this epidemic, which were previously neglected. With the increase in life expectancy for PLWHA (Crane et al., 2006; UNAIDS/WHO, 2006a), the country's new focus is to support PLWHA and their families in managing the long-term impact of HIV/AIDS (Government of Uganda, Uganda AIDS Commission & UNAIDS, 2000) so they can sustain themselves and continue to be functioning units in society.

Uganda's history with HIV/AIDS made the country a preferred place to conduct this research investigation on family coping with this epidemic's impact. The environment of openness, the fact that a significant number of PLWHA are now receiving HIV treatment, and the growing interest among Ugandan civil society in focusing on supporting people and families afflicted by this epidemic made Uganda an appropriate site to conduct the current study.

Defining the Case

The "case" in this study is the families, which included the widows, their children and relatives from the widow's and the deceased husband's side. Family friends were not included in the definition of the "case," but acted as an important additional source of data, providing an outsider's perspective on the families' experience with HIV/AIDS.

Data Sources

Data for this study were obtained from two sources: the case families, and the field notes taken during the data-collection phase. The first source of data included the family members who were interviewed during the course of the study: the widows, their sons and daughters, and the widows' sisters and brothers, as well as non-family members represented by some of the family friends who were also included in this study. All study participants were either directly from, or associated with, families afflicted by HIV/AIDS and had experienced or witnessed the difficulties presented by this epidemic and its related family loss. The study participants offered their personal views and perspectives on the hardships the families had to deal with, and on how the families managed these hardships.

Field notes originating from field observations were the second data source in this study. Field observations were made during each interview and were recorded after each interview as soon it was finished, and the researcher had an opportunity to expand the notes taken as well as to document any other visual observations and/or personal thoughts made during the interview.

Participants' Inclusion Criteria

Inclusion criteria were developed and used to recruit widows and other family members and non-family members to satisfy this study's purpose:

Widows' inclusion criteria:

1. Had lost their husbands because of HIV/AIDS prior to the interviews.
2. Were HIV-positive.
3. Were caring for at least one biological child from either the deceased husband or another partner.
4. Had at least a high secondary level of education (equivalent to the Ordinary Level).
5. Were employed in the formal and/or informal sector at the time of the conducting of the interviews.

Other family members' and non-family members' inclusion criteria:

1. Children participants had to be referred to by their mothers as family members who could answer the research questions and shed light on the experience of their families with HIV/AIDS.
2. Widows' relatives, particularly sisters and brothers, were referred to by the widows as being knowledgeable about the families' situation, and helpful to the widows and their children in dealing with the impact of HIV/AIDS, particularly after the husbands' death.
3. Other individuals, including friends and co-workers, had to be referred to by the widows as being helpful to them and to their children after their husbands' death.

In March 2005, ethical approval for the study was obtained from the Human Research Ethics Board of the University of Alberta's Faculty of Agriculture, Forestry, and Home Economics. After the researcher's arrival in the field and prior to the start of data collection, approval from the Ugandan authorities, specifically the Uganda National Council for Science and Technology (UNCST), was sought to conduct the study in Kampala city. The council granted its approval on April 21, 2005.

Recruitment Strategy

A purposeful sampling strategy was used in this study. Only individuals who satisfied the study's inclusion criteria, and who were able to articulate their beliefs and describe their families' situations, were invited to participate.

After arriving in the field (Kampala), the researcher made several visits to local non-governmental organizations (NGOs) working with PLWHA, mainly the Uganda

AIDS Commission (UAC), The AIDS Support Organization (TASO) and the Forum for People Living with HIV/AIDS (Forum for PLWHA). Through contacts made at the Forum for PLWHA and with the help of some of the staff there, a number of widows who were thought to satisfy the study's inclusion criteria were identified and approached for participation in the study.

Initial contact with potential participants was made through a staff member at the Forum for PLWHA, who introduced the study and asked permission for the researcher to contact them to further discuss their participation in the study. The widows who agreed to meet with the researcher were informed in detail about the purpose of the study and the requirements for their participation by using the Oral Request for Participation sheet (see Appendix A).

Twenty-eight widows who met the inclusion criteria were approached to participate in the study, and six widows gave their verbal consent to participate. Those who refused were reluctant to participate either could not schedule meetings to discuss the study or were not living in Kampala. Another three widows who also satisfied the study's inclusion criteria were recruited through the initial six widows. Nine widows were recruited for and interviewed in the study. This number was determined to be satisfactory to the investigated research question when data saturation was reached and no new information emerged when conducting additional interviews.

The widows provided an entry point into the families in this study and enabled the researcher to recruit other family and non-family members involved with the studied families' situation. In addition to the nine widows, the interviewed family members included some of the widows' children and the widows' relatives: four daughters, two sons, two sisters and one brother. The non-family members included the study were five female friends (see Table 1). More than one participant from each family and non-family group were sought to provide multiple perspectives about how the families were managing the long-term impact of HIV/AIDS. Only in one case was a sole participant, the widow, interviewed from a family. This widow refused to refer the researcher to other family members.

Table 1: Participants in the Study

Family Case	Widow's Age	Living Children's Ages	Family Members Interviewed	Widow's Non-Family Members Interviewed	Total No. of Interviewees
Beth's Family	42	14, 18 & 20	The widow, her daughter and her sister	–	3
Grace's Family	47	18 & 20	The widow and her daughter	–	2
Claire's Family	35	12	The widow	The widow's friend	2
Kate's Family	39	12, 14 & 16	The widow and her daughter	The widow's friend	3
Beatrice's Family	35	12, 13 & 14	The widow, her daughter and her sister	–	3
Juliet's Family	35	9	The widow	–	1
Margret's Family	44	20 & 18	The widow	The widow's friend	2
Carol's Family	42	11, 13, 15 & 18	The widow and her son	The widow's friend	3
Hope's Family	45	12, 13 & 14	The widow, her son and her brother	The widow's friend	4

Total No. of Interviewees	18	5	23

Data Collection

This section includes a description of the procedures and instruments used to conduct the interviews, the pilot-testing procedures, and the field observations and field-notes procedures carried out in this study.

Interview Procedures

Kvale (1996) describes the interview as a form of conversation which takes place between two partners to help the interviewer to "understand themes of the lived daily world from the subjects' own perspectives" (p. 27). Thus, the face-to-face interview format was used to solicit oral responses from the study participants. After they had orally agreed to participate in the study, all participants were asked to choose a place and time of their convenience to meet for the interviews. Prior to each interview, an information sheet was given to the participants to read, and their questions were answered. All participants could speak and read English. The information sheet included a description of the purpose of the study, the time required for the interview, confidentiality issues, the risks and benefits associated with participation in the study, how the collected data would be used, and the right to withdraw from the study (see Appendix B). Later, a consent form (see Appendix C) was given to the participants to sign and to signal their agreement to participate in the study.

Most of the interviews with the widows and their family members were conducted at their family homes. All widows were interviewed between two to three times to cover all the areas that needed to be discussed to understand their families' coping experience with the long-term impact of HIV/AIDS. Often, there were 6-to-12 week intervals between these interviews. The intervals were due to the widows' inability to schedule time for an earlier follow-up interview, usually because of work and family demands. The intervals were also required sometimes because of the researcher's need to review previous interviews to identify any missing information from earlier interviews, which may have been needed to be discussed in the follow-up interviews. The other participants, family and non-family, were interviewed only once. All interviews lasted between 60 and 100 minutes and were conducted in English and tape-recorded.

Interview instruments. Four different interview guides with different sets of questions were developed and used in this study with the widows, their children, and others including their relatives and friends, respectively (see Appendix E). The guides ensured that the interviews explored the issues of interest to the study from each group of participants: widows, children, relatives and friends. Two interview guides were used with the widows in order to cover all the issues needing to be discussed, while allowing time for building rapport with the widows through repeated visits. Rapport was needed in this study to help the researcher explore the widows' families' experiences with illness and death caused by HIV/AIDS. This issue could be painful to discuss with a stranger, i.e., the researcher, during the first interview. The first interview guide focused on discussing the hardships that the widows and their family members had encountered, particularly after the husbands' death from AIDS (see Appendix E-1 & E-2). The second guide focused on how the families had managed the impact of HIV/AIDS following the husbands' death. Special attention was paid to exploring what resources had been helpful to the families in their effort to cope, what had been least helpful, and what these families still needed to cope with HIV/AIDS' long-term hardships.

A third interview guide was developed for use with the children to explore their view of their family situation, their involvement in their families to help mitigate the HIV/AIDS' hardships, and the changes in their families after their fathers' death (see Appendix D-3). A fourth interview guide was developed for use with the widows' relatives and friends to gather information about these individuals' involvement with the widows' families, their perceptions of the challenges facing the widows' families, and what these families needed to better cope with the impact of HIV/AIDS (see Appendix D-4).

As a supplement to the interview guide for use with the widows, a demographic information sheet was used to gather information about the health of the widows and of other family members living in the same households, the family history with the HIV illness, the AIDS-related death and receiving of HIV treatment, and the family's socioeconomic situation (see Appendix D).

Pilot-testing of the interview guides. Prior to the actual interviewing, the guiding questions were pilot-tested with two families (two widows, one daughter and one sister) who satisfied the study's inclusion criteria. The pilot-testing used in this study helped to ensure the appropriateness of the wording of questions and their comprehensibility. As well, the pilot-testing helped with practical issues such as how to best approach potential interviewees, how to introduce the study both orally and in writing through the information sheet, and how to obtain their verbal and written consents. Verbal consent was obtained prior to the written consent, and both consents were obtained before tape recording of the interviews.

Following the pilot-testing, the following changes were made to the interview protocols:

- Introducing the study and the questions: Changes were made to the oral request form for participation to clearly describe the purpose of the study in detail during the initial contact with potential participants. In the interview guides used with the widows, an introduction and further clarification also were needed before asking questions about the family's sources of income to assure the participants that their income information would be used only for the study and that no one would have access to it but the research team.
- Language and content appropriateness: Re-phrasing of some guiding and probing questions, particularly when asking about the adequacy of the family finances, was needed. Thus, the meaning of the earlier question "Do you have adequate income for your family needs?" had to be specified. This question was re-phrased to include specific items to make it better understood. Thus, the question was modified to "Do you have adequate income for food, clothing, education, medications or other health care expenses and other necessary living expenses?" Also, changes were needed in the interview guide used with the children. Accordingly, the guide was revised to begin with questions about how the child was doing generally and particularly in school, e.g., "How are you doing?", "Do you go to school?" and "How are you doing in school?" These opening questions helped put the children at ease so they could answer the difficult questions on their family situation after the loss of their father. The researcher also learned to be more patient when conducting interviews with the children and to accept that

they might not have wanted to answer particular questions, such as those related to their health.

The pilot-tested interviews were not included as part of the data analyzed in the study because the changes made to the interview guides meant that the interview data collected during the pilot-testing differed from those of the actual interviews, for which the revised interview guides were used.

Field Observations and Field Notes Procedures

Field observation was the second data-collection instrument used. The interviewees' non-verbal communications were observed and noted by the researcher during the interviews. Thus, the researcher was able to gather information on the participants' tones of voice, emotions expressed, and the interactions which took place between the interviewees and other family members present during the time of the interviews. In addition, the families' homes were observed when the interviewer was invited there to conduct the interviews. Attention was paid to collecting data related to the socioeconomic status of families by observing the type of family home. This process included collecting information on the number of rooms and bathrooms, and the presence of assets such as cars, bicycles, radios, televisions, refrigerators, and cookers, which helped in validating what some of the widows said about their families' financial situation and the availability of physical resources during the time of the interviews. These observations were later typed into note form and became part of the data to be analyzed in this study. The researcher's personal thoughts about what had taken place during the interviews were also included in the field notes. The analyzed field notes data provided a description of the participants' characteristics and of the interviews' locations, which is included in Chapter 5.

Data Coding

This phase started when all the interviews' tapes and field notes had been transcribed into Word documents. The interview transcripts were verified against the audio tapes to check for accuracy. Coding of the interviews and field notes began with the broad organization of the collected data following repeated listening to the interview tapes, and the reading of the interview transcripts and field notes. All interview transcripts were first coded to identify each participant as a widow, son, daughter, sister, brother or friend. All the participants' formatted interviews and field notes were then entered into NVivo7 software to prepare the data for analysis. NVivo7 is software often used to analyze rich, text-based qualitative data and to maintain a hierarchical coding scheme (QSR, 2007). The software helped in creating and modifying the coding scheme over a period of 7 months of coding, organizing, and analyzing the collected data.

Coding involved the following:

1. Development of a coding scheme through
    a. Careful examination and re-reading of the transcribed interviews and field notes, and of the interview guiding questions to identify patterns in the transcripts that were related to the study purpose.
    b. Reviewing current literature on the topic of interest in this study to get a sense of the overall data available and to identify areas where knowledge was lacking, which could direct data analysis to look for answers to the missing information,

  c. Taking into account the theoretical assumptions used to frame this investigation, which helped focus the analysis on identifying certain data that addressed questions related to these assumptions and to the study purpose.

2. Coding of text and creating of categories
  a. Text from interviews and field notes were sorted into an initial group of categories, which matched the text segments included under each category.
  b. Further refinement of these categories was conducted through determining patterns among the categories and using categorical aggregation, which permitted combining of related initial categories to create fewer broader categories. Accordingly, three main categories were identified: impact of HIV/AIDS on the lives of the studied families, behavioral coping strategies of family members to manage the situation, and resources influencing family coping with the resultant hardships.
  c. Finally, development of sub-categories within each broad category, which contained specific data on particular issues related to the main category. The three main categories and their sub-categories are:

Category 1: Impact of HIV/AIDS on family members.

Sub-categories: impact on family members' health, impact related to loss of the husband/father's contribution, and impact related to the discrimination and social isolation resulting from being members of families afflicted by HIV/AIDS.

Category 2: Behavioral coping strategies of family members

Sub-categories: coping with the health, financial, and social consequences associated with the illness and death.

Category 3: Resources and family coping

Sub-categories: Education, employment, and social support

The interviews' and field notes' transcripts entered in NVivo7 were coded according to the identified categories. Several tree nodes were created by using NVivo7, and contained data on each category and its sub-categories. A node is a collection of references drawn from data transcripts about a specific theme of interest. Tree nodes are a collection of organized references in a hierarchical structure – moving from the general category at the top (the parent node) to more specific categories (the child nodes). This organization technique provides easy access to particular collections of references within the broader category when needed.

Data Analysis

The thematic analysis of the interview and field note data gathered for this study involved employing the cross-case analysis technique, which provided the basis for the identification of this study's main findings.

Cross-case analysis. This data-analysis technique was applied to compare the identified categorical patterns within individual cases across all the nine cases. This step helped in organizing the study's findings into three major themes: the changing family structure, the widows' assumption of the responsibility for their families, and the widows' actions to care for their families. These themes each had several sub-themes. As a result, the cross-case analysis provided access to similar and different experiences across all nine families in regard to how they had been impacted by the HIV illness and

AIDS death in the family. This analysis also identified the broad range of strategies the families had used to manage this epidemic's impact and how specific factors related to all the families' unique characteristics; e.g., how being headed by widows who were educated and employed had either helped or hindered family coping.

Confidentiality

Confidentiality was discussed in detail in the information sheet handed to the participants before each interview. The participants were assured that only the research team involved in the study, i.e., the researcher and the members of the researcher's graduate committee, would have access to either the original tapes or the transcribed data in their entirety. The participants were promised that in the written transcripts real names would be replaced by pseudonyms, and that anonymous quotations would be used in future publications, presentations, and written reports. The quotations included in this dissertation were modified to prevent identification of the study participants, so that real names, ages, places of residence, and place of work were either altered or not included in the quotes. The participants were promised that all the taped records and written transcripts of interviews would be kept in a secure location for five years and then destroyed.

The Study Rigor

As Morse (1997) described it, "rigor" involves anticipating and managing potential areas of biases that may affect the study, while ensuring its validity and reliability. The use of the multiple-case design had a distinctive advantage in ensuring the rigor of this study. Yin (2003b), and Herriott and Firestone (1983) suggested that evidence from multiple cases is often considered more compelling because of the possibility of predicting and replicating the study findings and, thereby, increasing the validity of the theoretical assumption(s) which framed the study. The nine families in this study experienced hardships as a result of HIV/AIDS, particularly following the husbands' death. The use of a multiple-case study design, which allowed for conducting cross-case analysis, permitted the identification of similar and different patterns of experiences among these families in regard to the hardships they faced and the strategies they employed to cope. The families included in this study had the same specific inclusion criteria because of the use of a purposeful sampling strategy, which helped in identifying some similarities in the findings across the families. These similar findings strengthened the study's rigor, which enhanced the study's external validity in regard to the experiences being shared across a number of cases in the study. As a result, the researcher was able to examine the theoretical assumptions used to frame this study by suggesting that these assumptions can be applied to other contexts (Yin, 2003a) such as the Ugandan context.

As Yin (2003b) suggests, establishing specific areas that need to be investigated is an important step in ensuring a study's construct validity. Therefore, in this study, the issues explored included the hardships the families had experienced as a result of HIV/AIDS, the coping strategies family members had used to manage these hardships, and what had been helpful and least helpful to these families in their effort to cope. Establishing these specific operational measures kept the researcher, who was also the data collector, focused on what information had to be gathered in order to achieve the purpose of the study and, in turn, improved the study's construct validity. Moreover, the use of multiple data sources, interviews and field notes, also called "data triangulation"

(Patton, 2002; Stake, 1995; Yin, 1994), enhanced the construct validity of the study's results because the findings from these different sources complemented and supported each other.

Using standard interview-guiding protocols with each of the three groups of participants ensured consistency among all the interviews conducted within each group and helped to increase the reliability of this case study's results (Yin, 2003a) since a standard set of questions was used with all the study participants. Before starting the analysis phase, all the transcribed interviews were checked against the tape recordings to make sure they had been transcribed verbatim and that the emotions expressed during the interviews had been captured in the interview transcripts. All these measures were taken to improve the reliability of the study's findings, so that the operation of the study, which involved the data collection and preparation for analysis procedures, and how the study results were identified, was understood in detail.

Finally, the researcher/data collector had spent time building rapport with the study participants through repeated visits and phone conversation made before the first interviews and, often, between the follow-up interviews. During the interviews, the researcher/data collector made sure to give enough time to the interviewees to gather their thoughts and remember what had happened. The researcher also showed understanding of and empathy towards what the participants shared with her during the interviews. All these techniques helped create a comfortable non-judgmental environment during the interviews and encouraged the interviewees to open up to the researcher and to share their private and detailed information, thereby increasing the reliability of the study's findings.

CHAPTER 5: FINDINGS

This chapter is organized into two main parts to provide an in-depth insight into the findings of this multiple-case study. The first part provides a description of the participants' profiles and the interviews' settings based on the field notes and demographic information sheets, which were used to gather health and economic data about the families in the study. In this part, the demographic information and field observations about the widows and members of their households, the settings where the interviews were conducted, and the socioeconomic status of the studied families are presented.

The second part provides the results of the in-depth interviews conducted with the widows, their children, and some of the widows' relatives and friends. The interviews directly achieved the purpose of the study, which was to learn how widows and children from families afflicted with HIV/AIDS had been managing their lives and coping with the long-term impact of this epidemic, particularly after losing the husband/father because of it.

Description of Participants' Characteristics and Interviews' Locations

The interviews were conducted in Kampala city, the capital of Uganda, between August 2005 and April 2006 with a sample of nine widows, six biological children (two sons and four daughters), three siblings (one brother and two sisters), and five family friends, whom the widows had identified. All the friends were women. In total, twenty-three participants were included and interviewed in this study. The widows' ages varied from between 35 and 47 years. The number of biological children in each family was between one child and four children. The widows had lost their husbands because of

AIDS between four and fifteen years prior to the interviews. None of the nine widows had remarried after her husband's death. Only five of the widows had received written wills from their husbands.

Most of the widows looked healthy with no obvious signs of the disease although they were all HIV-positive (see Table 2). The widows had become HIV-positive between four and seventeen years prior to the interviews. Seven widows had been on ARVs for between three and seven years prior to the interviews. In recent years, most of these widows had had free access to ARVs. Two widows, because of their high CD4 count, were not on ARVs, but were receiving treatment for opportunistic infections when needed (see Table 2). All the widows were of average weight and were clean and well dressed. Most of the children's HIV status was not known, but two children in two families had tested positive for HIV and were receiving treatment (see Table 2). The children, who were either interviewed or were met in their homes during the interviews, also looked healthy. They were wearing clean clothing and obeyed their mothers whenever they called on one of them during the interviews to discuss something.

Table 2: Family Members' Health Information

The Family Case	Widow's HIV & AIDS Status	Children's HIV & AIDS Status
Beth's Family	+ve for 12 years, on ARVs for 6 years	-One child +ve -The other 2 children's HIV status is *UK
Grace's Family	+ve for 15 yeas, on ARVs for 4 years	*UK for both children
Claire's Family	+ve for 10 years, not eligible for ARVs	*UK
Kate's Family	+ve for 17 years, on ARVs for 3 1/2 years	-One child positive and on ARVs. -The other children's HIV status is *UK
Beatrice's Family	+ve for 4 years, not eligible for ARVs	*UK for all children
Juliet's Family	+ve for 8 years, on ARVs for 4 years	*UK
Margaret's Family	+ve for 14 years, on ARVs for 7 years	-Son negative. -Daughter *UK
Carol's Family	+ve for 6 years, on ARVs for 6 years	*UK for all children
Hope's Family	+ve for 15 years, on ARVs for 5 years	-A daughter and a son tested negative. -One daughter's status is *UK

*UK: Unknown status

The widows' levels of education varied: three widows had a high school education, two had a university education, and four had a post-graduate education (a Master degree). Seven widows were employed in the public or private sector and, as a result, received a regular income every month (see Table 3). These widows were working in hospitals, public service offices, schools and in NGOs. Two widows depended mainly on informal employment, for each one operated a small private business: a poultry farm at home and a money-lending business. Five of the seven formally employed widows also had informal employment to generate the extra income they needed for their families. These business activities, which the widows called "Income Generating Activities" (IGAs), included selling agricultural produce, renting shops, and renting rooms in their homes. As well, all nine widows were involved with NGOs in Kampala, which were supporting PLWHA. The widows were members of these organizations who used to receive services from them and often volunteer their time to help other PLWHA who were associated with the organizations and with the communities where the widows lived. Most widows viewed their families as being middle class based on their socioeconomic status, but two widows indicated their families were of low socioeconomic status.

Table 3: Family Members' Demographic and Socioeconomic Data

Case	No. of Living Children	Education Level	Formal Employment	Informal Employment	Assets
Beth's Family	3	Secondary	No	Yes	Land, farm and her house
Grace's Family	2	Post-graduate (Masters)	Yes	Yes	Land, house and money in the bank
Claire's Family	1	Secondary	Yes	Yes	Land and bicycle
Kate's Family	3	Post-graduate (Masters)	Yes	No	Land, house, car, and money in the bank
Beatrice's Family	3	Secondary	Yes	No	Land
Juliet's Family	1	Graduate (University degree)	Yes	Yes	House, Land, car, savings in the bank
Margaret's Family	2	Post-graduate (MSc Degree)	Yes	Yes	House, car, land
Carol's Family	4	Graduate (University degree)	No	Yes	House
Hope's Family	3	Graduate (University degree) + a diploma	Yes	Yes	Family house and another house used for rent

Most of the interviews were conducted in the family homes. Three widows lived in houses that had been built by their husbands, who had willed them to the widows and their children. Another three widows did not own a house at the time of their husbands' death, but were able to build their own homes later on. The remaining three widows were living in rented houses. Those widows who owned their own homes had good houses built from brick. Most of these homes had a garden, a relatively well furnished living room, and a cooker, refrigerator, radio, and television. The widows who were renting had fewer belongings. Their homes did not have a radio and television, but had some cheap and, sometimes, broken furniture, a cooker and a refrigerator. All the homes looked clean, and some of the homes, particularly those owned by the widows and their children, had housekeepers. All the widows were interviewed more than once, but only one interview was conducted with each of the other study participants.

Interviews' Findings

The study participants provided data that helped to achieve the purpose of this study on how HIV/AIDS-afflicted Ugandan families headed by widows are coping with the long-term impact of HIV/AIDS, particularly after the death of the husbands/fathers. The participants usually focused on what had happened to their families after the husbands' death, but they also often compared their lives before and after the loss of their husbands. Therefore, some of the findings revealed the changes that had occurred within the families even before the husbands' death. The study findings relate to three main themes: the changing family structure; the widows' assumption of full responsibility for their families; and the actions taken by the widows and others, including family and non-family members, to respond to the families' needs. Each of these themes had several related sub-themes outlined below:

"The Changing Family Structure"

1. The 'Normative' View of Families in Uganda
2. Structural Changes During the Illness Phase
    a. The Couple
    b. The Children
    c. The Relatives
3. Structural Changes After Experiencing Death
    a. The Mothers and the Children
    b. The Family Size
    c. Relationships with the Couples' Kin

"The Changing Family Responsibility"

1. Becoming the Caregiver
2. Becoming the Head of the Family
    a. Providing for the Family
    b. Educating the Children
    c. Parenting Alone

"Actions Taken to Respond to Family Needs"

1. Staying Alive for the Sake of the Family
2. Managing Money Issues
    a. Facing a Decrease in Family Income
    b. Strategies for Managing Family Income

Theme I: The Changing Family Structure

The participants in the study reported that their family structures had significantly changed during their husbands' illness and after their death. The main events triggering the changes were the husbands becoming severely ill with HIV and later dying because of AIDS. The husbands' deaths provided the starting point for the study and the interviews, which allowed the researcher to gain access to the study participants' experience with the long-term impact of HIV/AIDS from the time when the husbands were dying until after their death. This point of entrance allowed the researcher to learn how the families' structures had changed during the course of the crisis.

The Normative View of Families in Uganda

In her description of what constituted a "family," one widow explained how families are viewed in the Ugandan culture. She mentioned an ideal, normative view of family structure and family membership in Uganda and hence of who should be included in a family:

> The family set-up in our country [Uganda] is a bit extended, and when you talk of family, you think of the children, your husband if you have one and your parents, brothers and sisters and the aunties and uncles. Those are taken as family members, but basically when we talk of the immediate family members, those should be your children and your spouse and parents. (Hope)

When describing their families before their husbands fell sick with HIV, the other widows expressed similar views about whom they considered to be a family member during that time. The widows identified their husbands and their children to be their immediate family members:

> My family, we were a family of four people, my husband, my daughter, me and my son. This was my immediate family. (Claire)

> My small family was my husband and my children. (Carol)
>
> My child and myself and my husband, this was my small family. (Juliet)

The widows talked about other people whom they also considered family at that time, including both the husbands' and the wives' kin. When the husbands were still alive, the families' kin visited and socialized with the immediate families:

> We used to visit my parents. We used to visit my mum during the holidays. (Kate)
>
> We used to visit them [the husbands and the wives' relatives]. Some of my sisters also used to come and visit, like this. (Beth)
>
> He [the husband] had relatives and they used to visit. My relatives also would come. We used to have good relationship. So those days [when the husband was alive], they [the family relatives from both sides] used to visit every weekend, and we used to have like a mini-party. (Carol)

Structural Changes during the Illness Phase

Following the husbands' illness with HIV, changes occurred in how the immediate family members and their kin related to each other during that critical period. These changes showed a complex, dynamic movement of family members either closer to or farther away from the family circle, depending on what was happening in the families while they were confronting the illness.

The husbands and wives stayed together and became closer to provide the care needed for the sick husbands, whereas the children became separated from their parents, particularly during the fathers' hospitalizations. The husbands' and the wives' kin were concerned about what the immediate families were experiencing, but each kin group was concerned with and involved in these families' lives in different ways and for different reasons.

The Couples

In this study's nine families, the husbands contracted HIV and eventually progressed to AIDS. As their health deteriorated, the husbands were hospitalized for between a few weeks and several months. During this period, the wives focused mainly on their dying husbands, devoting most of their time and effort to providing them with the care they needed while in the hospital:

> I remained with him, and even when he was sick, it was me taking care of him. He didn't want any other wife to take care of him. He wanted me, and I was with him till the last hour. (Beatrice)
>
> I had to care for him. I cared for him for about three years, but there were two hectic years, the last ones. And before he died, we were in the hospital. I was with him all the time. (Beth)
>
> I actually cared for my husband. I prayed to God to at least make him live for some time. I had to leave working because he needed me. (Carol)

The couples established a new residence in the hospital away from the family home to obtain the medical care needed for the sick husbands:

> I felt I have just to give him the comfort, I have to support him and indeed I did all those. We were in the hospital many days. (Claire)
>
> I had to care for him. We went to the hospital and I stayed with him all the time. We were in the hospital for six months. (Hope)
>
> He was hospitalized, and in hospital I had somebody who was helping me during the day, but at night I would go there, take over, in the morning I come to the office. (Margret)

The Children

The need to care for their dying husbands in the hospital required the wives to focus less on their children at home than the wives had done previously. This situation separated both parents from their children. The older children in particular remembered this separation and how much they missed seeing their hospitalized fathers. These children were also afraid for their fathers' lives:

> He was in hospital for so many months. My siblings and I couldn't see him. Only my mum was in the hospital. (Edward, Carol's oldest son)

> I was scared he is going to die and we [the children] didn't see him for a long time. (Evelyn, Beth's oldest daughter)

The families' neighbors and friends noticed the separation between the mothers and their children, reporting that the mothers, who were also wives, spent most of their time in the hospital with their dying husbands. As a result, the mothers had little time to be with their children, who were usually left at home:

> Every time now that the husband was sick in hospital, and the mother was in hospital with him, they [the children] were not interacting with the mother frequently. Maybe she [Carol] could come once in a week or twice, just to check on them [the children] but the man [the husband] stayed many, many months in the hospital. (Gloria, Carol's friend and neighbor)

> Her husband when he was sick and in the hospital, we used to help and give support at home and stay with the children, talk to them. She [Kate] was so stressed. She was with the man in the hospital all the time. He was very sick. (Mary, Kate's friend)

> Her mother came and stayed with her at home. She was helping with the children and Margret would be in the hospital. (Ruth, Margret's friend)

The Relatives

During the periods of the husbands' illness and hospitalization, the husbands' and the wives' relatives were engaged with the couples and their children in different ways and were motivated to become engaged for different reasons.

The husbands' relatives. The husbands' relatives were concerned mainly about the husbands' health and with giving their support to the sick men. The husbands' mothers and brothers used to visit the hospital where the husbands were staying to check how they were doing:

> His mother came to check on him. She used to come. Also, his brothers used to come and visit him even in the hospital to check on him you know, and when he was dying, they used to come more. (Hope)
>
> At least one of his brothers came to visit sometimes in the hospital. (Claire)

Some of the men's mothers came to the hospital to help with the caregiving needed for their sons:

> My mother in-law would sometimes come and visit in the hospital. When he became very sick, his mother came, and we were staying together. She assisted me care for him in the hospital. (Grace)
>
> His mother, his step-mother, was there in the hospital. She helped a little. (Carol)

One widow mentioned that one of her husbands' siblings had offered his support, mainly to help with the husband's medical needs:

> Sometime his brother, who was by then working abroad, sent some medicine when he knew [about the husband's illness]. He sent medicine for two weeks. (Carol)

On the other hand, in some families, some of the husbands' relatives were disengaged from the families during the husbands' illness, for reasons related either to the dying husbands or to these relatives' choice.

In one family, the sick husband, who wanted to hide his illness, isolated himself from his relatives:

> Because for him [the husband], he was a person who isolated himself from everyone, even friends. He even didn't want his relatives to know he was sick. I was the only one with him. (Beth)

In another family, the sick husband refused to see his relatives because he did not want them to suffer from knowing he was dying:

> He [the husband] had even refused … [pause] … He didn't want to go to the Mum when he was still alive because I asked him that you need IV drips, maybe I could ask my mother in-law to come and help me with you in the hospital. One of us can stay in the hospital, another one stay at home take care of the children. Then he said I don't want my Mum to see me or me to see my Mum. So, I am sure he didn't want to cause pain to the Mum or the mother to look at him when he was dying. (Hope)

Another widow described how some of her husband's relatives remained indifferent even after the man had been hospitalized:

> My husband was admitted, and one of his brothers found us in hospital, and I remember as he was going, my husband told him, "Don't go back home [to the village] before I see you. There are certain things I would like to discuss with you." But he [the brother] never came back until he [the husband] died. My in-laws neglected me when he was sick. When he died, I told them, "None of you bothered to come and see us in the hospital even when we called you," and we had an argument like that. (Juliet)

None of the widows reported that the husbands' relatives had been concerned about the wives or the children during the periods of the husbands' illness and hospitalization.

The wives' Relatives. The wives' relatives, especially the wives' mothers and sisters, were concerned mainly about the wives and their children, particularly when the husbands were hospitalized. Therefore, the wives' mothers and sisters were often present in the wives' homes to take care of the children and to help with the housekeeping:

> My mother came to stay with me when he was sick. She was there with the children. (Margret)

> Her mother really helped her. She stayed with the children. She would cook for them and keep the house. That is how she [Margret] managed. (Ruth, Margret's friend)

> My mother stayed with my children at home. (Carol)
>
> Her mother came to stay with the children when she [Carol] was in the hospital. (Gloria, Carol's friend)
>
> When he [the husband] was sick in the hospital, my younger sister was living with us so she could help a little with the children and keeping the home. (Beth)

Some of the wives' sisters also offered the wives moral support and counseling so they could deal with the husbands' illness:

> I told my sisters he was HIV-positive. They [the sisters] would come and see me, talk to me from time to time, counsel me. (Beatrice)
>
> My sister comforted me really. She was staying with us. She told me, "Don't despair." She gave me moral support. (Beth)

The participants did not report whether the widows' relatives were present in the hospital to visit and to help care for the dying husbands. However, the widows reported that only their female relatives were present in their and their children's lives during the time of the husbands' illness and hospitalization. The widows did not mention their male relatives being involved with their families during that time.

Structural Changes after Experiencing Death

The families continued to experience structural family changes, particularly after the husbands' death. These changes involved the mothers re-shifting their focus to their children. Also, some families experienced an increase or decrease in their households' size. Some families added new members to their households, whereas other families reduced their households' size to include only the widows and their children. Other structural family changes also occurred in terms of who from the families' kin stayed connected with the widows and their children, and who left the family sphere either immediately after the husbands' death or as time progressed.

The Mothers and Children

All nine widows reported that, after their husbands died, they (the widows) quickly shifted their focus to their children. The children became the priority of the widows, who worried about how their children would survive. Therefore, the mothers' main concern was to care for their children, most of whom were young when their fathers died:

> I said to myself after he died, "My children are my number one priority." (Beth)
>
> I wanted to be there for the children. I am the only parent left and my children were young at that time. (Beatrice)
>
> My life evolves around these children. You know he died when they [the children] were still very young. The boy was very young and didn't know what was really happening and even the girl, the girl was about six years. (Margret)

The widows indicated that their main worry immediately after their husbands' death was how they would take care of and provide for their children, who became their mothers' first priority:

> My children, I was worried about them. I am focusing on them. Who will help them, so I must take care of them, you know. (Beth)
>
> There was no one else but me to be there for my children. My first worry was how they are going to survive if I die. All I want is to take care and provide for them. My focus is on them. They are on me now. (Kate)
>
> I told myself what I should do, I should try my best, keep my children, they are still young, they need me. They need me more than any other time. They need me to take care of them. (Carol)

The Family Size

Sometime after the husbands' deaths, the households' size changed to include new members from mainly the widows' kin side. These new additions became part of the immediate family and were added to the widows' families, either to be cared for by the widows or to support the widows and their children in their effort to manage their lives after the husbands' death. In other situations, the family size was reduced mainly for economic reasons to include only the widows and their biological children.

Some widows mentioned that kin joined their households after the husbands' death. Some of these kin came to live in the widows' homes in order to be cared for by the widows. These additional family members included AIDS-orphaned children and these orphans' mothers and siblings, who were all members of the widows' larger extended families. The widows referred to these new additions to their households as their 'dependants' and often viewed them as members of their immediate family:

> My family now, I have my own biological child and the dependents. I have now ten people living with me. I have my daughter, my own biological child, I have two brothers and two sisters, I have the wife to my late brother and the three children who belong to my late brother. For me, I see them now as my family members. (Claire)

> My family as of now are my children and my immediate orphans, my sister's children am looking at. They are living with me after she died. (Margret)

> In my home, I have my children and two AIDS-orphans of a distant relative. They came to live with me after my husband died. I took care of them. They were young, now they are grown up. (Beth)

The widows mentioned that these dependants, who were sometimes AIDS victims, had nowhere else to go and had to live with and be cared for by the widows:

> So you see, I have one child and the dependants who I have nowhere to take them because these are orphans as a result of HIV and AIDS. They have no one to care for them, so I am the one taking care of them. (Claire)

> I call those [the dependants] my family because they are entirely upon me. You see, my sister died [of AIDS], and these children have nowhere else to go, so I took them. (Margret)

In other families, some of the widows' mothers, siblings and cousins moved in with the widows and their children in order to help care for the children and to assist with the household chores:

> My mum stayed with me till she passed away last year. She was my counselor, she was everything. I had to continue working, and I had those kids, who were still babies. She was the one looking after them. I would find her cooking food for the family. She was the one encouraging me to cope with the situation. (Margret)

> We share my house with my people whom I stay with. I have my cousin sister, and my cousin brother. They always stay with me here [at home], so we share the work load with them, and they give me company. They came to live with me after he [the husband] died. They came to help me. They are grown up now. They are my family. (Grace)

> When the husband died, I came to live with my sister. Yeah. I decided to help my sister. I stayed for seven years. I love my sister. She needed me. I came to help my sister and the children. (Peter, Hope's brother).

On the other hand, some widows had to reduce the number of people living in their homes. These widows found it too demanding to care for their biological children as well as other family members who were dependent on them. In some families, the widows asked their relatives who were living with them to move out of the family house. In other families, the widows did not allow additional relatives to move in with them. Both situations reduced the number of people who used to share the same family home before the husbands' death:

> My extended family, they were living with me and I just had to ask them all to leave. They were becoming a burden after he [the husband] died because I continued to care for them, provide and do everything and they expected me to do so although you had their

> contribution to my life was very, very little. And I didn't even have the energy to feed my own children. So the extended family became a burden to me. Then I said Ok, fine. I have to do something. I talked to my dad and my father said that Ok. I will take them. I will ask them to leave. It is enough that you can provide for your nuclear family, for your children. You don't have to take care of these other people and I will tell them to leave the house. So they left. They had to leave the house. (Kate)

> Staying alone is not a problem to me. I find it very easy these days to stay alone with my children alone at home. I don't need my extended family too much because since am working they expect too much from me. So I prefer to stay on my own and they stay away. It is better this way. (Beatrice)

> I prefer to stay alone. I try to reduce my cost so now I don't allow people to stay with me. I need every coin for my children. (Carol)

Relationships with the Couples' Kin

Additional structural changes took place within the studied families after the husbands' death. These changes involved the husbands' and the wives' kin's association with and presence in the immediate families' lives. The differences in the families' relationships with the husbands' and the wives' kin were dramatic.

Separation from the deceased husband's kin. In most of the studied families, a conflict between the widows and the deceased husbands' relatives occurred shortly after the husbands' death because of fighting over the inheritance. As a result, the relationship between the widows and their children, and the deceased husbands' relatives ended shortly after the husbands' death.

One widow explained that the cultural tradition in Uganda permits the in-laws to inherit a deceased husband's property even if the man has left a widow and children behind:

> Here [in Uganda] there is this idea that my brother had property, so when he dies, I need my brother's property. (Margret)

The widows in all the nine families reported that their in-laws were interested mainly in taking all they could get from whatever property the deceased husbands had left behind. In some cases, the in-laws were successful in seizing the property left by the deceased husbands:

> We had property up country and everything was taken [by the man's relatives]. (Juliet)
>
> They [the deceased husband's brothers] expected that they would get certain things. To them, it was like this woman has girls only, and they are boys, so they expected to inherit. (Kate)
>
> When he died, his relatives, his people from his side, they would come like wanting properties and those things. That was the main problem that she [the mother] faced. They [the father's relatives] would be bothering her. They want this and this and this. Like funny things, his clothes, furniture, these things. (Rebecca, Grace's daughter)
>
> The relatives from my husband's side, what they were thinking of was just property grabbing, and indeed they did it. They grabbed the property. They took the one land, the household property like chairs, tables, TV, what not, they just took it off. (Claire)

The in-laws also caused other problems for the widows. Some in-laws proposed widow inheritance, which meant one of the deceased husband's brothers should marry the widow. In one family, after the widow refused to be inherited, her in-laws began to abuse her:

> When my husband died I was in the village that is within the middle of the relatives of the man. After the death of my husband, my in-laws wanted to inherit me and wanted to inherit the things in the house. I refused. I didn't want to be inherited. So they started mistreating me. (Beatrice)

Some in-laws went farther and wanted to kill one of the widows, accusing her of infecting their son with HIV and, thus, causing his death:

> When he passed away I, was almost killed when we took the body home. Because they [his relatives] thought I was the one who brought the disease to him, and they didn't want to have a look at me. (Juliet)

As time passed, the husbands' relatives kept away from the widows and their children and, hence, were no longer part of the widows' and the children's lives:

> After the property thing, they [his relatives] all left. They never came back. (Kate)

> We buried him, and they [his relatives] all disappeared, I am telling you. (Beth)

> They [the deceased husband's relatives] are not very supportive to Kate, the brother in-laws. So it is, you know, in our culture the children belong to the father, and then you realize she [Kate] is keeping these children all on her own. They [the brother in-laws] don't help her or come to see the children. (Mary, Kate's friend)

> The people that didn't help me at all are the relatives of my children, especially from their father's side. When my husband died, I transferred to a new town. I wanted to separate from them because I knew the more I stay with them, the more I will get on loggerheads with them. They were not helping me totally. They are leaving the children for me, and they don't check on them. They don't help us at all. I know if I send them my children, they will not help them. They will not even buy a pencil for them. (Beatrice)

Only one widow and her children stayed in contact with some of her deceased husband's relatives long after his death. In this family, the father in-law kept in touch with the widow and the children:

> My father in-law comes. I have good relationship with him. Like two weeks ago he brought a cup, a big cup for my son because he had passed his exam. (Carol)

Changed relationships with the widows' kin. Some of the widows' relatives, mainly their mothers, siblings and cousins, remained in the family circle long after the husbands' death. Those relatives did not depend on the widows to care for them, but came to offer their support to the widows and their children:

> Her mother was very helpful. She was a company in the home and was there with the children. She gave her [Margret] strength. (Ruth, Margret's friend)
>
> After about two weeks after my husband died when everybody went then I got this cousin who I have told you has remained with me. She stays with me now. She came to stay as part of the family. She wasn't with us before the death of my husband. But after the death of my husband, my family also saw the need for me to get somebody else who is a bit more mature because now I would be the only grown-up in the home. So the family said to her, "Now you can go and stay with your sister to support her." In Africa, we call them [the cousins] sisters. (Grace)
>
> Peter [the brother] helped me so much. He decided to come and said he is going to assist me, he is going to be a family, he is going to be there. He really helped me. I would go to work in the morning, and he would do the business at home with the children, would take them [the children] to school, bring them back and feed them. Also, my relationship with my relatives didn't change. Now they feel they are concerned because they want to see me happy, and they have seen people in the village dying and what have you. They have seen what they are going through. So they want to continue supporting me. It [the relationship] hasn't changed. It has increased. It went even more, and they became closer to me. (Hope)

Not all the widows' relatives were supportive immediately after the husbands' death. Some of the widows' siblings stayed away from the widows and their children for a long time because these siblings were afraid of acquiring the HIV infection. These relatives also feared having to assume responsibilities for the widows and the children if they (the siblings) stayed connected with the families. Therefore, some of the widows' relatives decided to isolate themselves from the widows and their children:

> People became cold. They thought they will also get infected if they visit me. My sisters stayed with me only for one week after the funeral. They were scared also. They were fearing they would

> get infected. You could see they were scared. They would clean, but not washing my clothing. They were scared. At least my mother was still there, but she left after about three weeks. I didn't see my sisters for a very long time. (Carol)

> My sisters disappeared. All of them disappeared. Only one sister was there. They [the relatives] think you will become burden to them. So, all disappeared. I took a long time without seeing them. Now I tell people don't rely on relatives. (Beth)

As time passed, some of the widows' relatives, especially the widows' siblings, who were in contact with and supportive of the widows' families immediately after the husbands' death, continued visiting and communicating with the widows' families:

> I have three brothers and four sisters. They live very far away from me, but I often see them. At least, something like I can see them after every two months. We do the same. Sometimes I visit them, sometimes they visit me. (Beatrice)

> The real bothers and sisters, they are not staying with me. But they always come, as I have told you they come, they always come after two weeks. They were even here yesterday to check on me. (Claire)

The widows' kin, including the widows' sisters and brothers, also continued their relationships with the widows' children long after the husbands' death. These relatives offered the children some of the financial and moral support they needed:

> Uncle Jeff would come visit me in school when mummy can't come. He calls a lot. When I was in school, he would come and visit me on visitation days. Our visitation days were monthly. He would always ensure that at least he would visit me. If he cannot manage, at least he would send someone to visit me, a relative. My Uncle William, he has been as if he is like my father to me. He used to pay my fees. Even he facilitated other things if I need some money. Like for transport, it can be cloth or anything. When I ask for it [the money] and he has, he would give me. He really cares about us. (Rebecca, Grace's daughter)

> Now, I am even having the sons [Beatrice's sons'] here in my home. During holidays, they have to move to be with me, and we

> do chatting. We spend some happy time like that to make them wash away that orphanage feeling. (Liz, Beatrice's sister)
>
> When she (Hope) is away, I go and visit the children. I try to help. I try my best. (Peter, Hope's brother)

In some families, not all the widows' relatives continued to support the widows' families on the long run. As time passed, some of these relatives, especially the widows' siblings, began to stay away from the widows and their children and to return to focusing mainly on their own families, particularly as these relatives felt that the widows and their children were able to manage their lives on their own and, thus, were becoming less in need of these relatives' support:

> Now, I don't see them [her relatives] because like they would say, "She can manage." (Kate)
>
> My parents are still alive, I also have sisters and brothers, but each one has his own responsibilities. We meet very rarely, we don't meet so much. Some members of the family, some live in Kampala others live in other parts of the country. So each one fend for himself. They have their own families. At least they know I am doing ok. (Grace)
>
> My Aunties, they used to come like once in the year. It was last year. This year they have never come back, and they didn't bring us cloth this Christmas. They know my mum is working now. (Evelyn, Beatrice's daughter)

Overall, the data presented for the theme of changes in the family structure highlighted the continuous shifts in the family members' focus at different points of the families' experience with the crisis. These data also described the changes which took place in the families in terms of who among the family relatives stayed close to the widows and their children and who separated themselves from them. These structural family changes occurred during the period of the husbands' illness, immediately after their death, and later on as time passed. The data showed that the studied families' structures were fluid and dynamic as immediate family members and their kin responded to the dramatic events which were taking place within the families in relation to the husbands' illness and death.

Theme II: The Redistribution of Family Responsibilities

The husbands' illness and, later on, their death because of AIDS resulted in the realignment of the widows' roles and responsibilities. The widows' roles evolved from being those of the primary caregivers to their sick husbands to becoming the heads of their families after their husbands' death. Assuming the full responsibility for their families after their husbands' death required the widows to respond to some specific needs of their family members, particularly to the children's needs. Thus, the widows became responsible for providing for their families, and this new responsibility included educating the children. The widows also had to parent their children all by themselves.

Becoming the Caregiver

After the husbands were diagnosed with HIV, their health seriously deteriorated, and they required intensive care for variable periods of time. The caregiving responsibility was assumed mainly by the wives in the nine families. The widows reported that they had no choice but to care for their dying husbands because they (the widows) were expected to do so:

> He was very sick and bed ridden for like eight months, and I had to care for him all this time. I was the one doing everything. (Grace)

> I felt I have just to give him the comfort. I have to support him, and indeed I did all those. I really supported him. I really cared for him. It was my duty. I did what was expected of me as a woman. (Claire)

> I took care of him for six months. I was the one doing everything. I had to say, Let me take care of my husband even if he dies, am

> going to take care of him up to the last day, am not going to leave him here in hospital being thrown up and down. I couldn't let him just die like that. So, I took care of him until the last day. I was feeding him like a baby. (Carol)

Becoming the Head of the Family

Immediately after their husbands' death, the widows realized the enormity of the task of being the sole heads of their families. Some widows were prepared for assuming this role during their husbands' final days. Other widows started facing this responsibility only after their husbands' death. Moreover, all the widows felt overwhelmed after becoming fully responsible for their families. Being the head of the family required the widows to care, provide for, and educate their biological children, and also to become their father and mother. In some cases, the widows also became responsible for caring for other members of the extended family including children.

Assuming the Provider Role

In most families, the husbands were the main providers who cared for the financial needs of their wives and children. In some families, after the husbands became ill, the widows started preparing to assume the families' main provider role. After the husbands' death, all the widows became the main providers and had to respond to all their families' needs. Most of the widows reported that they had felt overwhelmed by their need to assume this role all by themselves:

> Ok, I may say that I think I was tuned into this [becoming the main provider] for the last two years before he died because he kept on breaking down slowly by slowly, and I saw him washing away. I was already tuned to his death. I had come up like I would be the sole breadwinner for the family because he was getting weak. I was like tuned into becoming the breadwinner. (Kate)

> Those days when my husband was still alive, we were a little well-off, I would say. We were middle-class family because my

> husband was working. He had a big job. So, money was not so much of an issue. After he died, I would wake up at night sweating, thinking how we are going to survive. All over a sudden, I became the main breadwinner. I was supposed to do all those things. (Carol)

> When he died, I knew now I had to take full responsibility. That's when I realized, "Oh, I am now the head of the family. I have to be responsible from A now to Z." I didn't know where to start. (Claire)

> He died, and everything was awaiting me. Honestly, I didn't think my life would continue. (Beatrice)

One widow indicted that she needed to provide not only money, but also care and love for her children:

> He died, and now I have to provide food for the family. I had to provide school fees for the family, the children. I had to provide care in case of treatment for the family and to provide all the love. I had to care for all the children. (Beatrice)

In one of the studied families, the wife was the main breadwinner when the husband was alive. However, this widow still felt overwhelmed after her husband's death, realizing that she was left on her own to provide for her family's needs:

> I was the main breadwinner in the family. I was making more money than him because I was more trained than him. After he died, I was now taking responsibility for everything. Although I was the main bread-earner, but this time after his death, I had to do all those things myself, and so it was strenuous, especially in the first year. (Grace)

Even the children in some families realized that their mothers were becoming solely responsible for them. These children, who were older when their fathers died, remembered the stress this situation imposed on their mothers:

> When my dad died, my mum was grief-stricken. I think she was very scared to take care of us. She is the one left now. She had to do everything now. (Edward, Carol's son)

> Now Mummy, my Mum she started to work so hard. She was stressed a lot because everything, every responsibility was now on her. (Rebecca, Grace' daughter)

Responsible for Educating the Children

The widows perceived their children's educations as one of the most important family demands that had to be taken care of. Some widows had high expectations for their children to finish university and maybe even go beyond, particularly for those children who were already doing well in school:

> I would always tell my family members [relatives] that my anxiety is that these children should get good education. This is what I want for them. For parents who are in my situation, the best thing we want to do is to give good education to our children, so if we can give good education to our children, that is a priority. (Grace)

> I wanted education for the children, and these children were making it for themselves. By the end of the term, you get the report card, and the kid has passed. They are bright children, so I didn't want to not let them go to school. (Margret)

> You see, education is very important. Education for the children is very important. I want my children to finish their education and do Masters. I hope to see them doing their Masters. (Hope)

> Oh, I have to say I would very much love them [the children] to be in school. You can see this one [the son] has done very well. I hope all of them would go to university one day. Even study more after university. Maybe do Masters. (Carol)

The widows perceived education as their way of helping their children and dependents to have a good future, which would, in turn, help the children to survive and prevent them from having to beg and be dependant on other people including their relatives. The widows perceived education as a way to equip their children with the skills they needed to get a job and to contribute to society:

> Education for my children was so important for me. I tell my children, "You people, for me I have survived with my little

> education, but for you, you will not survive if you don't have education. Education can be a way of getting a job." I wish my children could get better education, be employed in future, and at least to be independent. I know the relatives will not help them. (Beth)

> My education was the best investment I made in my life. That is why I want education for my children. If they have education and I die, I know they will be able to survive. I don't want my children to beg when I am dead. I don't want them to become beggars. I know no one will help them. (Kate)

> I really want my child and my orphans [the dependants] to continue with education. If they don't have good education, they can't survive. (Claire)

> These children, they need to go to school. They are growing tomorrow, and they will become useful citizens of Uganda so they need to be in school. (Liz, Beatrice's sister)

Some widows mentioned that education was particularly important because the unemployment rate was high in Uganda. The widows emphasized that without "papers," referring to school certificates, the children would not stand a chance of competing in the labor market:

> Yeah, unemployment is high, but here in Uganda you can't even get a job if you are not educated. At least if you have the papers [the certificates] you can compete. So many people have no jobs, but luck hits. If you have your papers, you never know, you can get a job. That is why these children [Carol's children] should go to school. (Gloria, Carol's friend)

> So, if I get a better job and be able to put them in school, and they accomplish their studies well, they stand a better chance of being competitive with other children. They can get a job when they finish, but it will be difficult [to get a job] without education. (Grace)

The children also talked about their desire to continue in school as long as possible. Some children associated being educated with having a good future:

> I want to be in school. I want to go to university. (Alice, Beth's daughter)

> I want to be in school as long as my mum can pay the school fees. I want to become a nurse. (Evelyn, Beatrice's daughter)

> She [the mother] would make sure that at least we go to school like that was her priority. She would always ensure that at least we go to school. I have always been in school. I love school. I was doing very well. Personally, now that I have at least reached.... I am going to go to university. God willing, if I pass and get maybe a good job, maybe my future will be bright because I have been in school. I have studied. I know if I do well in school, this will help me in the future. (Rebecca, Grace's daughter)

> I want to go to university because I want to get a career. The future is promising if we [the children] work hard, if we do well like in education, finish university, we probably get good jobs. (Edward, Carols' son)

Parenting Alone

Immediately after the husbands' death, the mothers had to assume the parenting role by themselves. Most widows said that the dual duty of becoming the mother and the father at the same time was difficult to fulfill:

> The man [the deceased husband] was so much in for his children. He really loved them. He cared for them, and when he died I became a single parent, and I had to do all those things the father did for them. (Beth)

> I had to become the father. I tried to play that role of a father and mother, which was very difficult. The little one would say, "Eh. But daddy used to buy for me this and this. Daddy used to do this and this." So, I had to fall in the father's shoes, try my best and also to struggle to give him those things like the father did. (Carol)

> I look at my child, and I feel sorry. She doesn't have a father. I tried to be also a father for her, but it is not easy, you know, to do both. She also needs a father. (Juliet)

The children also noticed that their mothers were struggling to play both parental roles at the same time:

> The most difficult thing is that my Mum now, she has to act like a father and a mother. Mummy worry a lot because she feels now

> she is the one to take care, she is a father, she is a mother.
> (Rebecca, Grace's daughter)
>
> The most difficult thing is the fact that we have no daddy. Only Mummy, Mummy she is Mum and she is Dad. You can see her struggling to do it. (Edward, Carol's son)

The data for the theme of assuming the families' responsibilities revealed the widows' commitment to caring and providing for their families. These data illustrated some of the issues that the widows identified as their main responsibilities towards their families during the different stages the families went through before and after the husbands' death. Fulfilling those responsibilities had been stressful for all the widows, who reported being overwhelmed by being the only provider and a single parent while being HIV-positive at the same time. The older children and some of the families' friends also depicted the widows' struggle to provide for their families and to parent the children while being all alone.

Theme III: Actions Taken to Respond to Family Needs

The widows took different actions and adopted several strategies to do whatever they needed to do to take care of their families. Accordingly, the widows explored different means to stay alive as their first strategy so they could care for their families longer. They also had to take care of the families' financial needs by pursuing different strategies to generate more income for their families. Finally, given the financial difficulties all the families were facing, the widows and their children had to learn how to budget by responding to the families' priority needs first.

Staying Alive for the Sake of the Family

All the widows were aware of their HIV-positive status before their husbands' death. The widows expected to have the same fate as their husbands, which was to die from AIDS. To fulfill their required roles and responsibilities towards their families, the widows believed that they had to fight for their lives and do their best to live as long as possible so they could take care of their children and other dependants. Accordingly, staying alive became the widows' number-one priority motivated by their strong desire to continue to care for their children, most of whom were young at the time of the fathers' death:

> I pray to God. In my prayers, I say "God, one thing, give me life." Life is still my number one priority. What I wanted is to live. I tell you, life was really a very big problem. I could not rest. I could not sleep when I knew that the drugs are getting finished tomorrow. I am telling you, I love my children, and I knew after the death of my husband with the experience I have seen, no one can take care of your children than you as the parent. (Beth)
>
> Then I had my [HIV] status to cope with. I had to look after my life because I knew that if I wasn't there, then almost everything would not be there. I think one of the things that pushed me to do all that I have done is because of my daughter. Because at that time I looked at her, she was so young. So I said "Now, if I am not there, who will be there for you? and I said, "You must be the reason why I must live." So, I did everything that I could to make sure that I live. So I attended to my health first. That was very important. (Juliet)
>
> I wanted to live so badly. I couldn't even think of dying. I refused to let people put the idea of death in my head. And when I looked at my children because the eldest one was six years who is twenty now, I have to be there for them. I told the doctor, "I don't have money, but you have to treat me and make sure you treat me well. Do you want me to die and leave my children?" I was determined to live. (Hope)

Realizing the importance of staying alive, the widows indicated that they had to invest in their health and get treatment so they could live longer. The widows purchased the drugs they needed, adopted a "positive living" attitude, and became open about their HIV-positive status. This openness helped them to gain the support of their colleagues at work, which, in turn, helped the widows to maintain their health. As the years progressed, all the widows included in the study were able to access free treatment, which helped them stay alive and prevented their health from further deterioration.

Soon after their husbands' death, these HIV-positive widows bought expensive medications, participated in drug trials, and joined health care and research centers in Kampala known to offer treatment, care, and support for HIV-positive people:

> I was worried about how I am going to live those days [shortly after the husband's death] because the drugs were very expensive. I know with the mercy of God and with the drug we [HIV-positive people] can live. So I invested so much within my health. I started buying ARVs at 200,000 shillings every month. Having money like a lump sum like this one it is too much really, but every month I would be taking 200,000, because I wanted life… I wanted life that was my first strategy. I said, "Let me look for life first of all... eh." The money was my husband's gratuity, which I got. Very few people were on ARVs those days, but you see, they can work. So, I got it. It was just a trial to see whether I can live for some two years. (Beth)

> For me, the first strategy was to accept that I have the problem [being HIV-positive], and that means I am already vulnerable in terms of health status. So the first strategy was to make sure that I cater for my health needs by attending regular hospital services, health services. I go for all my appointments, and I go for any other additional hospital services, which I need. So first, I had to address my health, although it is not a hundred percent, but I am comfortable, and I have a very good relationship with my doctors and nurses. Every time I need their support, I just go [to the public hospital], and they attend to me promptly. So that is one achievement that I think I have scored. (Grace)

> ARVs had just started [shortly after the husband's death]. I had even made moves to get to the medical centre where they were giving the ARVs, and I had even volunteered to be one of the first people they were testing the drugs on. They had some drugs they were giving me, but apparently I think I didn't respond. So, when I got the attack, the doctor at the treatment centre said, "You know, there is a joint clinical research centre. It is the big centre here for HIV research." I didn't wait. I went there immediately. I had even got the director there, and he was monitoring me. At that time, I didn't want to die, I can't die. Actually, one time somebody came to me and told me she would take me to another centre where they were offering drugs. So, I also went there. (Margret)

The widows continued to seek medical advice to stay healthy. They learned to adopt what they called a "positive living" attitude, which was taught to them by the counselors in the different health care facilities they attended. As the widows described it, the positive living attitude had specific components that helped them to take care of their health and, thus, to live longer:

> I took care of my life, myself, by living positively. I went for counseling and am still attending ongoing counseling. They [the counselors] told us about positive living. Positive living, it has some components, and in these components we have things like proper medication, balanced diet, we have avoiding pregnancy, and if you want to produce, you have to use things like Nevirapine [a drug used to prevent mother-to-child-transmission of HIV during pregnancy and labor], caesarian section, but for me, I have chosen now to do without children. And then practicing safer sex, but for me, I have chosen now to abstain. That is my lifestyle I have chosen, and I want to stick to it. And there is this issue of avoiding alcoholic drinks. Me, I don't take alcoholic drinks. I make sure I have enough rest. Whenever I am tired, I just rest. I take care of my health. (Claire)

> This positive living was very helpful. They [the counselors] trained me in the positive living. This was how to live positively with my virus, and I had to go on improving slightly [improving her health condition]. (Beatrice)

> What helped me most was living positively. I accepted my situation, and I now know how to take care of my health. This is very important. (Beth)

Some widows also became open about their HIV-positive status. This openness helped them to lobby their colleagues at their place of work to help them when they were sick by supporting the widows' health needs. Through this openness and the colleagues' support, the widows were sometimes able to prevent further deterioration of their health:

> And then in my place of work, my workmates are very supportive because I am very open about my status. When I am sick, I tell them, "Today, I cannot come to work because I am not feeling well," and my head of institution is very cooperative, and my colleagues in the department, in my department, are also very cooperative and they cover for me. So that's another strategy I thought was very important to share my problems with my workmates, so that they can support me, support my health. So now I am here thirteen years after his [the husbands'] death, and I think I am still living. (Grace)

> When I started falling sick on and off, I had to disclose to him [the boss at work] then I had to disclose to the district [district officials] so that they can transfer me. They understood my situation. They transferred me again, and I am in town in Kampala, and I am near the main hospital such that I can access treatment when I need it. My workplace also supported me. (Beatrice)

The widows also talked about how their health needs were being met in recent years when HIV treatment, ARVs, became available in Uganda free of charge in some hospitals. Accordingly, all the widows were able to access ARVs for free along with the treatment for other opportunistic infections associated with HIV/AIDS. Having free access to treatment gave the widows a sense of relief, for they knew that they could afford to take care of their health needs without incurring any costs. Therefore, the widows became less afraid for their lives than they had been previously:

> Luckily enough right now, I am getting ARVs free of charge. I don't spend any money on my medications. So that one I have achieved it. I will die when it is my time for death. But I am not going to die as I would have died in 1998 [when the husband died]. (Beth)

> We are getting ARVs freely and the other Septrin [a medication for an opportunistic infection]. We get them freely, and this treatment for opportunistic infections is free. So, at least I am ok now. (Carol)

> As for now, medical expenses we are just lucky. The hospital where I am getting services, almost all the services are free because we are having even free access to antiretroviral therapy. And we are also getting free access to treatment for opportunistic infections. So that is just it happen to be that my hospital is one such hospital that gives free access to medication. So I was able to enroll in free treatment. I am not spending much money on medication really, and that is one thing which is making my life a bit comfortable. I don't think I would be able to afford antiretro viral therapy comfortably if I had to pay for it. (Grace)

As a result of taking the medications, some widows felt that their lives had almost returned to 'normal' because of the improvement of their health:

> Now, me I personally, I look at myself like anybody else who is not HIV positive. In fact, for your interest, I even sometime forget that I have HIV, because I am living normally, unless I am sick. (Grace)

> You see, now I don't see any difference between you and me. I am living a normal life, and my health is good. I am satisfied. I will die like any other person. If the day comes, I will [die]. (Beth)

Challenges to staying alive. Shortly after their husbands' death, the widows tried their best and took deliberate actions to treat their illness and to stay alive, but taking care of their health needs was difficult at that time. The main health challenge the widows faced soon after their husbands' death was their inability to purchase the medicine they needed to control their illness. Around the time of most of the husbands' death, HIV medications were not offered for free in Uganda and were expensive to buy, particularly for the widows included in the study, who lacked financial resources immediately after their husbands' death. As a result, for different periods of time, some of the widows had to go without the treatment they needed:

> So, when I was at this physician's [office], she says, "Now maybe we could do an HIV test. I said, "no…no…no, I did that a long time ago." So, she said, "Oh! You did it? What were the results?" I said, "Am positive." She said, "Then we can start you on ARVs." I said, "What? I don't have that money for ARVs. I can't afford it." One time I had to take only two medicines not the three because I had no money. (Hope)

> Because those days [shortly after the husband's death] medicine was not there. So, they [the people] expected me to die anytime. Then I tried to buy the medicine, which was very expensive. There was a time when I stayed for six months without medicine, I didn't have the money, but I just lived by faith that one day I will get free medicine, but I was sick all the time. I thought I would die. That was really difficult. I didn't have any money, but now I have free medicine. (Carol)

> And then when I became weak [shortly after the husband's death], buying medicine became another problem. This one time actually when I went to the clinic they told me when you start on this medicine, you have to take it everyday, but to tell you the truth, there reached a time when I didn't have the money to buy medicine. (Beatrice)

Even though the widows tried their best to stay healthy and were relieved to have access to free ARVs and to the other treatment for opportunistic infections, they were still worried about their health in the long run. The widows worried about their ability to continue to access free mediation in the coming years and also about a possible deterioration in the quality of the health care services they would be receiving in the future. Thus, the widows identified these two concerns as the greatest challenges to their health in the coming years:

> You see, the free treatment program will end after few years, and we don't know what will happen next. This makes you worry sometimes, what will happen. (Kate)

> Fortunately for me, these ARVs came, and I am on them, and these days I am getting them for free. Free treatment really helped me stay alive. I don't know what I will do if it is not there. Anything

> can happen …. This is going to be very bad for us [if we don't have access to free treatment]. (Carol)

> Our situation [health situation] is still difficult. The issue of medication, because the treatment that we are on is supposed to be for five years contract. If that expires, we [HIV-positive people who are receiving free treatment] see problems of quality of care changing which is a source of stress for us, but we don't know yet. But we know that the program will end after five years. Of course, they may renew it or what, but as we know of now, we don't know what will happen. (Grace)

Therefore, the widows expressed their need for continuous access to sustainable and affordable medical treatment, which they expected to continue to need in the future. They also wanted reassurance that they would receive good quality health care as well:

> The first thing we need really is to have sustainable services for treatment. If they [the treatment services] can be there all the time, and we adhere on the drugs, that is good. It is very important to have it [access to treatment]. (Beth)

> We need to have free access to the ARVs always. We need reassurance [that free treatment will be there always]. You see, also now the care we receive is good, and now we have good quality care. The quality can be affected, and that is an issue for us because coming from better care, going to poorer status is not desirable. It will affect our health. We need quality care. (Grace)

Challenges to the health of other family members. The families faced other health-related challenges in regard to caring for the health needs of other members. In particular, some widows experienced a health challenge regarding knowing their children's HIV status. In most families, the children were healthy, and, therefore, some mothers mentioned that they did not see the need to test their children. However, in most families, the main reason for not testing the children was the widows' unwillingness to accept and deal with the probable HIV-positive diagnosis of their children. Some widows were aware that they were denying their children access to proper treatment if they happened to be HIV-positive. Therefore, these widows sought professional help by undergoing counseling that would prepare them for testing their children and for a possible HIV-positive diagnosis of any of them:

> My children were not presenting any signs of health problems, and I already tested positive, so the target for the medics was to address my health and to them, since the children were seemingly healthy, it was not a priority [to test them]. And another thing is that, as mothers, we find it very, very difficult to accept positive results for our children. We would rather cope with our diagnosis and that of our partners than that of our children. (Grace)

> I have not tested her [the daughter]. I am planning to do it, but it is not something that is very easy. It is not that I prefer not to know. But really it has been difficult. I have been struggling to do it, but it is still not easy. Supposing I found she is HIV-positive, so I have to also be prepared to do it, and at the same time, I have to prepare her so that we all can live with this situation. It is very painful to see your child suffering. (Juliet)

> I want to know her status [the daughter's HIV status], but I am still preparing. Am now under going counseling to receive the results. I know it is not really easy if the results come out positive, and I am not fully prepared. That is why I want to be fully prepared when I take the girl for testing. I know it is her right to medication, and I feel if I test her early enough, if she is positive, she can be on drugs and I know she can survive, but I still want to prepare myself to receive her results. It will be very difficult for me if she is positive. (Claire)

Some widows listed other reasons for not having tested their children. The widows were afraid for their children' lives because the current HIV treatment was not a cure for the disease. Some widows also talked about their inability to have another child if one of their children died because of HIV/AIDS and, as a result, wanted to not know about this possibility. Therefore, the widows were delaying having to cope with the positive HIV diagnosis of one of their children by not testing the children:

> Because at that time [after the husband's death], especially, there were no good interventions for caring for children, and maybe they

> would die in such pain, that we generally want to disassociate ourselves from it. (Grace)

> Testing the children is not something easy, it is not easy. It needs a lot of courage, because I know now if they, I don't wish them to be positive, but suppose the child becomes positive, what are you going to do? They will need the treatment, but now I will be tortured somehow, you start thinking so much. At this age, you can't get another child under PMTCT [Prevention of Mother-to-Child Transmission]. You find your child is positive, the drugs, which are there it is not a cure! The drugs don't cure, we are taking it, it helps us to live somehow, but they don't cure. If God can help me, the ones which I have not tested, they become negative. (Beth)

Managing Money Issues

Money was an important issue for all the families included in the study. The study participants reported that a decrease in their families' income after the husbands'/fathers' death had affected the families' ability to respond to the family members' needs. The widows described the different strategies they had adopted to manage their families' basic needs. These strategies focused on having more than one source of income and on budgeting.

Facing Decrease in Family Income

The study participants identified several reasons for the decrease in family income, including the loss of the husbands' income, the depletion of the families' savings, and the in-laws seizing the families' property.

The family members identified the loss of the deceased husbands' income as the main reason for the decrease in family income immediately after the husbands' death, particularly in households where the husbands had been the main breadwinners:

> He was making more money than me. At first, it was very hard because my earning was less compared to the income [needed]. It was very less compared to the demands I had to deal with. I feel

> the income itself is not really enough to sustain me and my children. (Beatrice)
>
> After he died, in fact even the money reduced at home. There was some little money, I mean, it was not enough. (Alice, Beatrice's daughter)
>
> He [the husband] was the main breadwinner. He could provide each and everything, so I found out I have lost someone very important, and money became a real problem for me. We didn't have money. Being one source of income it is very difficult. Life changed because when he was alive, we were better off. But now, we are living in somehow life which is not so admirable. (Beth)

In most families, the family's savings were spent on caring for the dying husbands during their sickness and hospitalization. This situation further decreased the financial resources available to the families after the husbands' death:

> It was really so bad because he was sick for about two years, and we almost spent all the coins that we had. When he died, there was no money left, nothing. (Juliet)
>
> He had made enough savings and during his sickness, he was the one actually treating himself because he could sign cheques, tell me, "Go and get money. You have to buy this and this," and at that time, the antiretro viral drugs were not there. We only had Proconazole, so we were spending so much money on Proconazole, and it was expensive. He was treating himself, so by the time he died, he had left very little money on the account, very little. (Margret)
>
> He was admitted to hospital, and we spent so much money buying the medicine. We had some savings, but it was not enough. His work also contributed in buying the medicine, but it was not enough also. He died, and life became very difficult. I had no money left, and I had to take care of everything. (Kate)

In some families, the in-laws' seizure of property also contributed to the reduction in the financial resources available to the widows and their children after the husbands' death. The families who did not have a will written by the husbands lost their property to the in-laws:

> We had property up country … and everything was taken, but I said, "life has to continue." So, it was really so bad to have lost my husband, but also to have gone through what I went through after he passed away. He didn't leave a will, and I think that is why I went through all that I went through. They [the in-laws] took everything. I told them, "How do you expect me to care for this child [the daughter]?" but no one seemed to bother about her. (Juliet)

> They [the in-laws] grabbed the property. They took the piece of land, the household property like chairs, tables, TV, what we have, they just took it off. They said those property belongs to their late brother. So I felt like just giving them off. And indeed, they took it. If he had prepared, like if he had written for us will, we wouldn't have been suffering like we are doing today. But because he didn't write a will, I was tossed here and there, and we have been suffering. We didn't have the money to help a little after he died. (Claire)

Strategies for Managing Family Income

After their husbands' death, the widows needed money to respond to their families' needs, which included the families' daily living expenses, the children's education, and the family members' health needs:

> I need the money for food, I need the money for medication, I need the money for educational support for my child and for my dependants. And I have to provide for them things like clothes. They can't do without that. (Claire)

> Money is so important. I have to look for it everyday. I need to pay for everything. We need to live, eat and have education for the children. (Carol)

> I need money to pay for these children. As they get older, education is getting more expensive. I need to be ready with their school fees. (Hope)

> I have to raise the school fees for my children. I have to provide each and everything for them. (Beatrice)

Family members, mainly the widows, adopted several strategies to manage financially, which included having different sources of income and budgeting.

Obtaining different sources of income. To meet their families' financial needs, the widows had to expand their sources of income by being both formally employed and self- employed, and accepting financial assistance from other sources, mainly from the widows' relatives and some community organizations.

Formal and informal employment constituted the main sources of income in all the nine families included in the study. All the widows had been formally employed before their husbands' death. Some widows were able to keep their formal employment after their husbands' death, which provided their families with a regular monthly income:

> I have been employed for almost 25 years now. I get my salary every month, and we survive like this. My main source of income is my monthly salary from work. This is my stable income. (Grace)
>
> I have been working since 1984. My employment helped me be where I am today. (Margret)
>
> My work [formal employment] is my source of income. (Beatrice)
>
> I have been employed now up to 19 years. I have to make sure that I go to work. I had to be working and to work real hard to sustain my family. This is my source of income you know. (Hope)

Some widows had to hold more than one formal job because they needed the extra money to meet their families' financial needs:

> My sources of income, now I have this job and I am lecturing in the university. I used to sometimes work in three jobs. Working for three jobs was very difficult, but at least I could have the money, and I could have the money to generate more income for my family and to provide for my family and even put investment for my family (Kate)
>
> I have my job, and I also do some consultancy work with those organizations [organizations working with people living with HIV/AIDS]. There is nothing else. It is only those two that I do. At least it is a little bit balanced this way. At least when I do some bit of consultant work, I can have enough money slightly to that lowest income, but when it is not there and it is only my job,

> sincerely, it is very hard. I find it very hard when I do one thing so I have to do something else. At least I try. (Beatrice)

> I was working in a hospital, and I was also working in another job. I would go to my regular work, then from there try to find somewhere part-time work. I managed to find part-time job. You know, I was collecting money all the time. (Hope)

In addition to earning a monthly salary, some employed widows decided to start private businesses to generate more money in order to meet the families' financial needs:

> After he died, I used to do tailoring business on the side. I said I better take this skill seriously. It was good business, but I stopped after some time. Now, I have a poultry farm around the home. This is for the daily income. What we get from the poultry is just for feeding and paying the basic needs. Also I recently got a business in a salon where I engage some boys to do the salon work that is working on men's hair. They give me money every week. (Margret)

> I have some small business that I am running. So that one I do it in the evening. I come from work in the evening. That is the time I spend, you know, doing some side activities bringing in side income. I bought a vehicle that does commercial work. I also have a shop where I sell stuff, small shop. (Juliet)

> My brother and I did a grinding of salt business. We would bring sacks of salt with big, big stones, and this machine would grind it, and we were fortunate that a shop could take what we grinded and sell it. (Hope)

Those widows who had lost their formal employment either before or shortly after their husbands' death depended mainly on self-employment, which provided their families with their main source of income. These widows had what they called "Income Generating Activities" (IGAs), which they often managed by themselves:

> Sincerely speaking, the only source that I can call somehow permanent income is just this poultry farm, my income generating activity. I get something [some money] every month. Every day I sell eggs. I buy feed for the poultry, then what is left can be my monthly earning. My income generating activity, it really

> improved my income. Not improving alone, that is my earning … that is my source of income. It sustained me and my family. (Beth)

> What I do, I lend money to people at a certain rate. This is my source of income. I also supply food to those very schools where my children are studying. I sell raw food, dry food stuff to boarding schools like posho, beans, sugar and cooking oil, and I would mostly supply to schools where my children are studying. (Carol)

Income from formal employment and self-employment was very important for the widows and their families because it provided them with the financial support they needed to survive. However, each type of employment had its own challenges.

Challenges with formal employment. Some of the formally employed widows lost their jobs during their husbands' illness or shortly after their husbands' death. The widows' frequent absence from work while caring for their dying husbands, and the discrimination they faced at their place of work because of the suspicion that they were HIV-positive, were the main reasons why some widows had lost their formal employment:

> I had to care for him [the dying husband] and within the process, that is when I lost my job caring for him, and also because I was on and off at work. One week you are at work, two weeks in hospital, no one would tolerate. I was irregular [sometimes absent from work], so when I went back [to work] they [the employers] told me you are ever absent. My boss wrote a letter to the District officials. So I was accused because the district officer said that my boss is ever complaining. You are ever absent! Hm! So I was fired from work. (Beth)

> Because when my husband died, I was back to my employers. They told me they had recruited another person. I was working as the accountant, and so they told me if I wanted to continue working with them, I would do the same work of an accountant, but I would be paid a lesser salary of a clerk. So, I thought it was their polite way of saying they didn't want me since they had known that he [the deceased husband] had died of HIV. Then I got employed with another microfinance. I worked there for six

> months, but later they told me, aah, they didn't want me. What I learnt later is that they thought I am also infected, and I could become a problem to their company. Say if I died, they would have to pay all those expenses [benefits]. So, they told me the business is not doing well so, they can't take me. So I left. (Carol)

> The regulations at that time [shortly after the husband's death] didn't favor my situation [being sick with HIV] because the rules stated there if I don't finish my course and my research within one year, then I will be fired from my teaching position and I will lose my job, and that is exactly what happened because I took this year-one year off. I was very sick. I was almost dying. I had to take a leave, but they asked me to leave my position, and I had to leave. So it was very tough during that time, particularly when I was not employed. (Kate)

Dealing with formal employment challenges. The formally employed widows tried to overcome the difficulties they were facing by adopting specific strategies by improving their skills and obtaining their employers' support. Some widows felt their vulnerability at their workplace and went for more education to strengthen their positions there and their employability in the future if they lost their jobs. Having a second degree also helped some widows to increase their income:

> I had terrible pneumonia, which was almost to kill me. Now, when I fell sick, I was on-and-off, on-and-off [from work]. After I recovered and went back to work, they wanted to restructure me out as I told you. Of course, because I was sick, and they thought the procedure or the criterion was to get out the sick, the inefficient, and, of course, when you are sick, you are inefficient and they wanted to get rid of me. Then I knew my first degree was not enough, so I went for further education. I did a Master degree. I said this would help me improve on my skills and my knowledge, so that I could be used else where in case the company here felt they no longer need my services. I would get them [the jobs] elsewhere. Of course, I would have added on my knowledge. (Margret)

> I think my education has placed me where I am today, and I think it is very important. It was my husband who insisted that I do a Master degree. He told me while he was sick, "Why don't you do this degree? You never know, this may be what will help the

> family." Now, I just present my papers when I want a job, and I will get it. (Kate)

> My employment made me what I am, and I also had the desire to add on because I would not take good care of the children if I didn't have a job. So, I had to go back and study, so I did this diploma. That was 2001 when I was almost dying, and everyone said, "That one won't finish the course." I said, "I will complete it, am determined, and this is my future." The first job I was doing was paying me, and they kept on increasing a little. But now after I did another degree, I am being paid more than the salary I used to get. (Hope)

Some widows also became open about their HIV status with their employers. This strategy enabled the widows to obtain the support of their employers, who, in some cases, reduced the widows' workload and helped the widows keep their jobs.

> My boss supported me. I told him I was HIV-positive and that I need my job. I was not cut off from the payroll, but it didn't mean that I had to strain at place of work. I did what I could, and what I couldn't, I left. (Grace)

> I teach three days a week because I have explained my problem to my head teacher and I have disclosed myself status to him. So, at least I rest for 2 days. But this didn't affect my salary and I was able to keep my job. They (the employers) really support me. (Claire)

> And people I was working with were very understanding! Sometimes, they would ask me ….because they said "You can't sit at home." After his death I tried to isolate myself. I was at home. They (colleagues at work) came and pulled me from home. They took me and said "You are not coming to work, but come and sit in this office. We can't let you stay at home. You see this support helped me not to lose my job. That was important. (Hope)

Challenges with informal employment. Some of the widows who had a business in addition to their formal employment or who were only self-employed also experienced challenges as they struggled to manage and profit from their private businesses. The main problem the widows faced was being cheated by others who had become involved in their private businesses. As a result, the widows lost money, but some of them indicated that they had no choice but to stay in business because doing so was the only way for them to earn money for their families. Also, although they lost money, some widows saw what had happened as an opportunity to learn about the process of managing a private business:

> Ok. Me, all the small business I have tried to put up, the people I am asking to run them are eating up all the money. For example, I had started selling second-hand shoes. I could buy them and because I am very busy, I could send them to some people in the village to sell them for me. When you go, they don't give you the money. They just tell you stories, stories ….the money is finished that kind of stories. Then I also tried to buy smoked fish and also give it to some other people from some village to do selling for me. At first, I was getting some money, but after some times, again I had to drop it. I was getting nothing. (Beatrice)

> When I got the money, the pension after he [the husband] died, I tried to do some business. People would come. Friends would know that I have got money. So they would say, "So, let us do business." But they ended up cheating me. So I ended up selling the land we had to get money, but now that money is finished. That is why I have mortgaged my house to the bank and got money, which money now I lend to people. I continued with the lending business. At the time, I thought that business [lending money] would be better, and also there are people who pay. Other people, they don't give you the money. They don't pay back sometimes, and it brings headache. You keep thinking whether they are bringing it back or not. Of course, this is business. It is a risky business, but you have to do business to survive. You can't just sit there and say "This business is risky, I am not going to do it." You will not eat. It is a very risky business, but on the way you learn. You learn very many things. (Carol)

Receiving support from others. The widows and their children received financial support from external sources to help them manage their financial needs. This support came from two sources: the widows' relatives and community organizations such as the Church and the NGOs working to support people living with HIV/AIDS in Kampala city.

The widows' relatives either gave cash to the widows or helped to reduce the families' expenses by providing food and sometimes helping to pay the school fees and the medical bills of needy family members:

> The relatives from my mother's side were helpful at least. Sometimes when I am hard up with the school fees, my sister can top-up to give me some topping of the school fees. Sometimes my mother sends me food from the village because where I am staying in is town and food is expensive. My mother sends me food from the village, so I don't have to spend money buying food for several months, and this helps a little. (Beatrice)

> My family supported me very much, especially my parents and my siblings and also a cousin of mine. They supported me very, very much. My siblings, they pay my children's school fees, and this is a very big contribution. They really supported me, so I was able to deal a little bit easier. Even medications, they [the siblings] contributed. They gave me money, and paid for some months of my medication until I was able to enroll on a free access to treatment. (Grace)

> We actually had some Auntie of ours who came and helped us in trying to get money to take our mother to hospital, and she started to make money for us to go to school. She did everything for us. I mean like to provide some food. (Alice, Beth's daughter)

In one family, one of the husband's relatives provided material support to the widow and her children after the husband's death:

> My father in-law comes. He brings for me some small things like food, hens that is birds. (Carol)

Organizations working with PLWHA, as well as some religious institutions such as the Church, also helped some families by providing some material support to the widows and their families so they could meet their essential needs:

> For the first year, I was being supported by my family, my parents and secondly, since I came out, and thank God, for me, am open. I came out, and I was also being supported by organizations like NCWLA (National Community of Women Living with HIV/AIDS). They also supported my children in educational support, provision of scholastic materials like books, pens and

> mattresses, and then also sometimes they were giving us food and on top of that they were giving us support like with IGA. So somehow they helped me, and it would be a supplement to what I was providing these children, which was good for us. (Claire)

> I am very active in the AIDS work. I got real help from some of these organizations. Like for me, the first medication I got first was a contribution by TASO (The Ugandan AIDS Support Organization). They [the people at TASO] said: This woman must not die. If we can afford it, this lady should not die. So they put, they contributed, they gave me money, and paid for my medication for sometime. (Grace)

> The pastor in the church helped us so much. At the beginning we used to get food from the parish, oil, sugar and what have you. (Hope)

Some of these community organizations also helped the widows with their businesses:

> Then the pastor helped us with the business. I told him my brother knows about machines, and he helped us get the grinding machine, and this is how we started the business. (Hope)

> The local leaders, the church leaders, they have been sending people to me, because I couldn't start an organization alone. They are helping me to stay in doing my business. When there is some one who wants information, they send this person to me. So local leaders, they are resource to me, and that is how I continue. (Beth)

Challenges to receiving support from others. Some families did not receive support, particularly material support, from other sources including the family relatives. The widows indicated that poverty among their kin was the main reason for not receiving material support from them. Some of these relatives also had their own families to take care of and, therefore, were left with little or nothing to share:

> Ok, some [relatives] came, but if somebody comes, gives you 5000 shillings what is that? My relatives are poor, I told you. I may be better off [than them]. (Beth)

> But you see, my relatives are not all that rich. They are very poor themselves, and I can't expect anything. I can't expect much from

> them really. My family, they have tried to be helpful to me, except that their income is not all that very high, and they also have children to care for. They try what they can, they try at least. (Beatrice)

> They [the relatives] would like to help. I feel it all the time, but they are poor people. They don't have that much to share. (Hope)

Learning to budget. Another strategy the widows and their family members adopted to satisfy their basic and most important needs was learning to reduce the family expenses. The widows, who were the head of their families, made budgeting decisions for the whole family by eliminating and/or reducing certain family expenses.

The widows learned to plan how they were going to spend the little money they had by prioritizing their families' needs and abiding by their spending plans:

> What I had to do, I had to accept, to economize. I learned to budget. (Beth)

> I am avoiding like various things. I know I have to plan properly and make sure I don't waste the little resources I have. And always I budget my things, and I stick to my budget. I don't go out of the budget because I have to put priorities in what I am going to do, and I make sure I implement. I spend the money as budgeted only on the necessary things. (Claire)

The widows completely stopped spending on entertainment and significantly reduced or completely stopped buying new clothes for themselves and their family members:

> All of a sudden he dies, so that word entertainment it came out of my vocabulary so if it is not part of my brain, it is not part of me. I don't think about it. (Kate)

> Also, like financially, we have to go back on some expenses. We have to lower. We had to cut things like fancy cloth, going out, entertainment and all of that. (Edward, Carol's son)

> Entertainment is not there. Then after that the clothes it is also affected. I don't go in for any more new clothes. For the children,

> no Christmas clothes, nothing like that. We don't have it [the money]. We have to budget. We have to force it like that. (Beatrice)

The widows also used fewer utilities at home and reduced their families' quality and quantity of food. These changes affected the children, who had to accept them:

> For the bills, it was only electricity and I was so strict that we were going to use electricity on one thing. We have been strictly using two bulbs in the house. I also tell my kids eat whatever I give you and be grateful. As along as we feel full, we are comfortable. (Beth)

> I forced myself to manage because there is no alternative. I had to change all my way of life style. All this good feeding I could not do it often with my children and I kept talking to my children and they also knew there was a big change in our family life and they had to bare with it. We look for the cheapest food possible even if it is not nutritious we don't mind. We now just eat, now we just eat, eat to live. (Beatrice)

> About food and what to eat we actually ate poorly. The food wasn't nice as it used to be. We ate vegetables many times. We had to live like that. (Evelyn, Beatrice's daughter)

Furthermore, some of the widows had to put their children in cheaper schools to reduce the family expenses:

> In fact, in fact sometimes she [Carol] had even to change the schools to get a nearby school, which is a bit cheaper, no cost involved. When the children at school, there at school they will have their lunch, they will have their supper there, and for you here at home, you just do what ...you have to look for little something for yourself to eat. (Gloria, Carol's friend)

> I told you, its only one daughter who is in boarding school. The others are in day school. It is cheaper [in day school], but then I feel it is not the best I could do because I wanted them all to be in a boarding school, but I can't afford. (Beatrice)

In their effort to keep their children in school, some widows negotiated with their children's school officials about the school fees. In most cases, the widows were allowed to pay these fees in installments, so that their children could remain in school:

> I need to also to budget for that and plan to pay school fees for the children. Now what I do because these children are many, I just have to pay just bit, bit. I pay in bits. I pay at least some little money for individual children and always promise their head teachers that if I get money, I will just pay in bits and then complete their payment. My request is always considered by the head teachers where these children are studying. (Claire)

> I used to go to these schools and negotiate with the bursars. I told them my position. I said look here, am a single parent and am a widow. I want you to help me. I don't want these kids to not be in school. I cannot manage paying full school fees at a go [at once]. So I was telling them [the school officials] what I want is for you to tolerate me in paying these fees. I will be paying whatever I can afford and whatever I send you, please receive it and let this child be in school. At the end of the term, I would have managed. I would have sorted out all these fees. I had six children in schools. Actually, they tolerated me, so I used to pay part and this is how I managed. (Margret)

Keeping the family inheritance. In addition, more than half of the widows included in the study stated that they had written wills left by their late husbands to protect them from the in-laws' desire to take all or share some of the family property after the husbands' death. Some widows said their husbands, expecting their relatives to cause problems about the property, had decided to leave a written will and to leave everything to the widows and the children. In other situations, the wives insisted that their husbands should leave a will. In both situations, the husbands left written wills for their wives and children, which helped the widows who owned houses before their husbands' death to stay in their homes and keep the rest of the properties:

> My husband protected me very much from his relatives, he protected me thoroughly. He was very sick and we kept on talking and we even went into writing a will. He said "You come here and we write it together." We wrote the will together and he started warning me "Be careful about this one, about this one." I insisted that he leaves a will. So he left a will and also he told his parents, his relatives that "When I die, leave my wife in that house and the

> children they should remain in that house." So my in-laws could not take away the house where I am. (Carol)

> He cautioned me about his relatives. He said "You know, I know they are so demanding. They are likely to come and disturb you after I die, but stand on your own. Guard against people who might come and disturb you." And he had put it in a will that no body should disturb her because whatever she has is for my children and he had made a portion of his savings to his mother. It was his idea. I was not there when he made the will. I was not around when he made the will. (Margret).

> The will, it was so important. After my husband died they [his relatives] wanted to come and share some of the property we had and I said "No. The will stated clearly who will take what and when and my husband said that "Ok, the land is for this, the house is for my wife to stay in and to raise the children." The car, I told you we had a car before he died, he said in his will that "My wife is sick, she can't commute easily and she needs the car because this is the only way for her to move back and forth and that is why she needs the car so the car is for my wife. The cows is for my children, they need the milk for their nutrition and may be they can sell some of the milk so they can raise some income." So the will stated clearly that all the properties, all the stuff that we had belonged to our family. My late husband made sure that no one will disturb me after his death. Therefore, without the will, we would have been in a lot of trouble. The will helped us to keep those things [the property]. (Kate)

Challenges to keeping the inheritance. Some widows were unable to keep their deceased husbands' property and to prevent their in-laws from taking it. These widows identified the lack of a written will by their husbands as the main reason for losing the family inheritance. Their lack of understating of the seriousness of the disease and of the imminence of death, as well as their unwillingness to help their wives, made some husbands refuse to leave a written will for their wives and children. As a result, the widows lost their property to the in-laws, who took everything:

> The relatives from my husband's side what they were thinking of was just property grabbing, and indeed they did it. I took the matter to court. I filed for letters of administration and up to now as I talk,

> since 1996 up to now, the case is still in the court. So, he didn't help me to plan, He was in denial [in denial he would die]. Although we had with him some 2 plots, and if he had prepared like if he had written for us will, we wouldn't have been suffering like we are doing today. But because he didn't write a will, I was tossed here and there because he didn't leave for us a will. Yeah, they took everything. That is why we are suffering. (Claire)

> He didn't leave a will and I think that is why I went through all that I went through. Because we used to have these small discussions when he was down. Many times we would discuss that issue [the issue of writing a will] but every time I would bring it up he was like "You mean you have given up on me, you mean you want me to die, you mean you don't trust my people." And finally, he passed away without a will. So after he died, everything, everything was taken. (Said Juliet in a sad voice)

The data presented for this theme revealed the actions the widows had taken in order to satisfy their families' financial needs. In some families, being able to keep the inheritance helped these families to have some financial assets they could rely on after the husbands' death. However, the widows' employment, either formal or informal or a combination of both, represented the main sources of income for these families. In some families, the widows' kin and local community organizations provided some material support, which assisted the families to manage financially. In addition, the family members accepted that they could afford to pay for only necessities, which were mainly food and the children's education.

Summary of the Findings

Overall, the data presented in this chapter revealed the struggles within nine HIV/AIDS-afflicted Ugandan families and the determination of the family members to survive and to continue to exist. Major structural changes began to occur in these families during the period of the illness, and continued after the husbands died. In addition, the death of the husbands and the HIV status of surviving family members had presented the families with enormous challenges and extensive demands. The widows had to adapt quickly to either the increases or decreases in the size of their households and, most of all, to their new responsibilities as the heads of their families. During the period of family adaptation, some widows lost their property to their in-laws, and all the widows had to struggle to earn enough income to support their families by taking on a second job, operating a small family business, and/or changing their financial priorities. At the time of the interviews, all nine widows were facing many challenges, but all were hopeful that they and their children would not only endure, but also prosper. As Juliet stated, "I see the future better," and Edward, Hope's son, said, "The future is promising."

CHAPTER 6: DISCUSSION

Existing research on the HIV/AIDS impact has been limited to investigating its destructive consequences on individuals, families and communities and has ignored how those affected have been coping with the epidemic. This study's findings contributed new knowledge on how families adapt to the hardships caused by the HIV illness and AIDS death in the family. This knowledge's practical implications are discussed in this chapter. Directions for future research are also presented by highlighting areas still needing to be explored in order to improve the understanding of family adaptation to HIV/AIDS' long-term impact.

Families Adapt to Crisis

Evidence from this study showed that HIV/AIDS-afflicted families experience changes in how members function during the crisis, particularly in regard to how they respond to the crisis at the beginning and over time. The evidence also indicated that HIV/AIDS-afflicted families can be resilient in their effort to adapt to the disease's long-term impact.

Family members' responses to the illness and death. Western literature has documented that crises cause family members to rethink their established pattern of functioning to accommodate the new demands imposed by the crises. Therefore, family members need to engage in a dynamic process of negotiating how they should function to keep the family going as the crisis's impact continues and changes (McCubbin & McCubbin, 1993; Tak & McCubbin, 2002). The literature states that this process requires some planning and rearranging of how family members can best allocate their efforts and utilize their resources in order to cope with the hardships.

Evidence from the current study suggested a different attitude by family members from what has been previously described in literature on family coping, particularly when dealing with the illness phase of the crisis. The husbands' illness and hospitalization period caused confusion and chaos among family members, who seemed unprepared to plan how to balance between keeping their families functioning while dealing with the demands of caring for the husbands. The need to respond first to what was perceived as urgent and as a family obligation influenced the wives' decision to support their husbands. For example, two widows reported, "He was dying, I had to care for him all this time" and "I did what was expected of me as a woman." Focusing on allocating support where it is most needed during a crisis can result in abandoning other family members and leaving them uncared for, as the findings from this study demonstrated. Some of the children were left at home with little care while their parents were staying at the hospital, trying to deal with the illness.

Relatives also responded to the illness and death in the family by lending their support to their relatives in crisis. A long-standing belief has been that the African kin network, including that in Uganda, is the safety net for the African families, particularly for families afflicted by HIV/AIDS (Adams & Trost, 2005; Ankrah, 1993; Case et al., 2004). Evidence from this study both supported and contradicted this belief. In this study, the finding that some relatives from both the husbands' and the wives' sides offered to help at different times during the crisis supported earlier research findings on the presence of kin support in African families. Careful examination of data revealed that this family support was targeted to help specific family members during the crisis: the man's relatives supported him in the hospital, while the wives' relatives helped to care for the children at home.

Another interesting finding from this study demonstrated that the crisis' progression can influence the presence of family support and may cause some relatives to cut ties and others to become more involved with the family members in crisis. In most families in this study, the husbands' death terminated the widows' and children's relationship with the men's relatives, but strengthened ties with the widows' relatives for some time. Moreover, this study also showed that signs of recovery and the ability to handle the situation can indicate when to start reducing family support. When relatives noticed that a widow was "doing ok" and "working," they began to withdraw their support.

Thus, blood linkage appeared to influence who among family members received support, suggesting that the more direct the blood linkage was to a family member, the more likely relatives were to support this member. However, the fathers' relatives in the studied families were an exception. Tradition in patrilineal African societies considers the children to belong to their fathers' family (Jankowiak et al., 2005), but, in this study, the fathers' relatives did not follow this tradition. Although the children were directly related to their fathers' relatives, but these relatives ended their relationship with the children shortly after the fathers' death. The above findings suggest that the conventional belief that African kin always support other family members, particularly during a time of crisis, may not always be true.

Another family response to the HIV/AIDS crisis involved some surviving family members' assuming a vital family role, the family provider role. Evidence from this study showed that all the widows had accepted taking on the role of the family provider after it became vacant following their husbands' death. Women in developing countries, particularly in the context of HIV/AIDS, have often been described as the primary caregivers of the infected family member and the caretakers of the children from HIV/AIDS-afflicted families (Kipp et al., 2006; Olenja, 1999). The role of African women as providers in HIV/AIDS-afflicted families is still not understood. On the contrary, women in HIV/AIDS-afflicted families are often described as vulnerable and dependent on others to provide for them and their families (Barnett & Blaikie, 1992; Mills, Singh, Nelson, & Nachega, 2007).

In this study, the notion of women's vulnerability in HIV/AIDS-afflicted families was challenged when the widows assumed the unconventional role of the head of their families and became responsible for responding to the different needs of their children and others who depended on them. The widows' perceived inability to count on others, including relatives, to feed, shelter, treat and educate the children motivated these mothers to become their families' main providers.

Moreover, the current study added new knowledge on family resiliency in the context of HIV/AIDS, which has not been discussed before. Evidence demonstrated that the studied families were able to adapt to the hardships the families experienced during the illness phase and after losing the husband, who had been the family provider. The widows' ability to stay alive, in spite of their HIV-positive status, for many years after their husbands' death, keep the children alive, keep sending the children to school, acquire new skills and resources through employment and higher education, and invest in their families' future in spite of sometimes losing the family inheritance and lacking adequate support from relatives and the community, all indicated these families' resiliency. These family achievements suggest that HIV/AIDS-afflicted families do not always surrender to the devastating impact of HIV/AIDS, but pursue active strategies to manage it.

The demonstration of resiliency within the studied HIV/AIDS-afflicted families contradicts the last twenty years' research findings on the impact of HIV/AIDS on families (Ankrah, 1993; Barnett & Whiteside, 2002; Gibb et al., 1991). These findings continue to describe HIV/AIDS-afflicted families as a "burden," in need of lifetime support from different sources, and often dependent on others (Barnett & Blaikie, 1992; Chimwaza & Watkins, 2004). However, most of these studies investigated the poor HIV/AIDS-afflicted families in rural areas (Barnett & Whiteside, 2002; Kipp, Tindyebwa, Rubaale, Karamagi, & Bajenja, 2007). In contrast, in the current study, the heads of the studied families were women living in the city who had some basic personal resources, including a certain level of education, and employment. These inclusion criteria focused the study on investigating the experience of families in Kampala who were faced with illness and death because of HIV/AIDS and whose members, mainly the widows, possessed some basic resources. Therefore, the differences between this study's findings on family coping and the findings of earlier studies could be attributed to the presence of personal resources within the studied families in addition to the presence of some level of family support and access to free treatment, which allowed the widows to have better health than the rural PLWHA, so that the former could continue to care for their families. These resources could be the reason behind the studied families' resiliency.

Practical Implications

Evidence from this study highlighted some situations where the widows and their children were most vulnerable and thus, could benefit from the provision of some specific support. These situations included the parents' inability to care for the children while dealing with the crisis, the parents' unwillingness to deal with a positive HIV diagnosis of their children, the loss of the family property, and stigmatization because of HIV/AIDS.

Inability to care for the children. The illness and hospitalization period resulted in the separation of the parents from their children at home, leaving these children with improper care, often for long periods of time. Assistance with child care from some of the mothers' relatives was helpful, but not sustainable. The course of HIV/AIDS can be several years with periods of severe illness and recovery (Piot et al., 1992; Weeb, 1997). Care for the children in the family can be interrupted during the illness and the period following a parent's death when the surviving parent becomes responsible for responding to additional family demands. Therefore, new ways to provide consistent care and support for children from HIV/AIDS-afflicted families, particularly during the time when the parents are overwhelmed by the hardships caused by this illness, must be found.

Identifying and dealing with barriers to HIV testing. Another practical implication of the study findings is related to the parents' inability to deal with several HIV-positive diagnoses in the family. HIV/AIDS is known to cluster in families (Gupte et al., 2007). Therefore, knowing the HIV status of all family members is necessary in order to address the health needs of all the infected members (Squires, 2007). This study's finding indicated that some mothers were reluctant to test their children for HIV.

This reluctance, which has not been mentioned before in the literature, suggests that the desire to care for the children and the fear of receiving a positive HIV diagnosis for them can be conflicting issues for parents contemplating testing their children.

Some of the mothers in the study, in order to avoid the psychological pain associated with receiving a positive diagnosis for their children, decided not to test them. This finding is particularly interesting because it came from a group of women who were educated and who were all aware of their HIV status after being tested either before or shortly after their husbands' death, and many of them were receiving treatment. However, the psychological trauma of witnessing their husbands die in pain from AIDS and experiencing early grief in the couple's life; associating AIDS with death; being HIV positive themselves and experiencing several periods of ill health because of the disease; having to struggle financially to get treatment and, later on, to secure access to free treatment; realizing that HIV treatment does not cure, but only prevents the progression to full-blown AIDS; experiencing stigma, social isolation, discrimination and lack of adequate support from family members and people in the community; and fearing to watch a child die prematurely were some of the reasons which prevented the mothers from testing their children.

This finding, although limited to the situation of the nine studied families, further suggests the possibility that HIV testing is a challenge not only for the poor families in rural areas, as previous studies reported (Sarker, Sanou, Snow, Ganame, & Gondos, 2007), but can also be a challenge for families with educated and employed mothers, even when the parents are aware of the illness' seriousness and the availability of treatment options. This conclusion helps explain why programs for managing pediatric

AIDS are not as successful as they should be, particularly when compared to the relative success of programs for managing HIV/AIDS in adults (UNAIDS/WHO, 2006b). A practical implication of this finding is the need to design interventions to respond to the different needs of all members of all age groups in the afflicted families, particularly the children's health needs, by identifying and eliminating the barriers to accessing existing support systems for PLWHA and their families.

Enforce inheritance laws and defend the human rights of PLWHA and their families. A third practical implication of this study is the need to manage some of the economic and social hardships caused by HIV/AIDS, such as the loss of the family inheritance and the stigmatization of the afflicted family members. The dispute over inheritance has been a constant problem for HIV/AIDS-afflicted families in many sub-Saharan African countries, where in-laws have been grabbing family property whenever possible (Adams, 2004). In this study, the finding that all the widows in the nine families had to fight with their in-laws over the inheritance supported earlier research results (Mendenhall et al., 2007). In this study, in families where the husbands had left a written will indicating clearly how they would like their properties to be distributed after their death, the widows and their children were spared property seizure by the in-laws. In families with no written will, the in-laws were able to take hold of the family property.

Certainly, this finding points out areas where help is needed for women and children in families afflicted by HIV/AIDS, particularly in patrilineal societies like that in Uganda, which advocate for the rights of men and their relatives over the rights of women and children (Adams & Trost, 2005; Ankrah, 1993). Enforcement of inheritance laws can be an effective approach to help widows and children retain their family resources after the husbands' death. Also, educating PLWHA, both men and women, about the importance of leaving a written will to protect their families could be a useful strategy to prevent disputes over the inheritance in case of an adult's death in the family.

NGOs in Kampala have been encouraging and helping PLWHA to leave a written will for their families (National Forum of PLWHA in Uganda, 2005). Some of these NGOs like the National Forum of PLWHA in Uganda have developed and distributed booklets to educate PLWHA about the need to prepare for the future by, for example, leaving a written will for their families (National Forum of PLWHA in Uganda, 2005). This service should be expanded to help PLWHA in the cities and rural areas to plan for their families' future so surviving family members can avoid further hardships, particularly financial hardships, after an adult death in the family because of HIV/AIDS.

As well, the widows in this study reported the continuing stigmatization of and discrimination against PLWHA, which still cause them to suffer social isolation and to lose their employment. The Ugandan government and different local NGOs have been working for years to combat this negative impact of HIV/AIDS on those afflicted by the illness and has achieved some progress in this area (The Health Rights Action Group, 2004; The Private Sector Alliance on HIV/AIDS, 2004). However, the continuing perception of PLWHA as a burden and of the illness as fatal (Ankrah, 1993; Kipp et al., 2007) is not helping to eliminate discrimination against PLWHA, even in Uganda, as this study's findings pointed out. The new findings in this study, which portrayed the studied nine families as resilient and able to become self-reliant for several years after the husbands' death, depict a different and hopeful image of individuals and families afflicted by the HIV/AIDS epidemic. Recognizing these families as resilient can be helpful in changing society's negative perception of them and in eliminating the stigmatization and discrimination they continue to experience.

Directions for Future Research

Building on the new knowledge from this study on family coping with HIV/AIDS, future research could focus on further exploring the issue of resiliency among HIV/AIDS-afflicted families, which is yet to be fully understood, by investigating how these families move on with their lives despite all the difficulties they often experience as a result of the epidemic. Understanding family coping with the long-term impact of HIV/AIDS is particularly important in the current era of increased access to ARVs, which has led to the perception of HIV/AIDS as not a killer disease, but a manageable chronic illness (Bernays, Rhodes, & Barnett, 2007). This new reality means that an increasing number of family members in the developing world will live longer and will experience the long-term impact of HIV/AIDS. Therefore, future researchers should investigate how these families cope with this epidemic over time and what is needed to support these families in the long run so that they can continue to be active participants in society.

As well, comparative studies could be conducted to compare the coping experience of families headed by widows, widowers, children and extended family members such as grandmothers, which represent the different types of families that have been created by HIV/AIDS (Mills et al., 2007). This kind of investigation could help to determine how each type of family manages the long-term impact of HIV/AIDS and how the children are cared for in these families. Comparing the situations of these families would help in understanding their different coping strategies and in highlighting areas of vulnerability for each type of family, and thus, would assist in developing evidence-based interventions to help these families cope better.

The issue of how family relationships are defined and structured, particularly when families are faced with a crisis, is another area requiring further investigation. In this study, it was clear that family support was targeted to benefit some family members and to neglect others. Thus, it could be useful to investigate how relatives of PLWHA envisage their roles in supporting these people and their families, and what motivates relatives to offer their support. More information about this issue could be used to help identify times during the HIV/AIDS crisis when the family may lack kin support and thus require support from other external sources in order to manage the crisis.

Future work might also focus on identifying the barriers to HIV/AIDS testing in afflicted families, where the disease is expected to affect more than one person. Conducting such research is particularly important in an era of increased accessibility to HIV treatment, which can help prevent the premature deaths of people from the different age groups in the population. The data from this research could be used to understand the exiting barriers to HIV testing in afflicted families, particularly in highly endemic countries where HIV testing is crucial to HIV/AIDS prevention and control. This information could later be used to inform the design of effective strategies that would combat those barriers and increase the utilization of HIV testing and treatment programs, thereby reducing the spread of HIV and the number of death from AIDS.

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APPENDIX A: ORAL REQUEST FOR PARTICIPATION

Appendix A: Oral Request for Participation

My name is Insaf Hag-Mousa. I'm conducting a research study as part of my PhD in Family Ecology in the Department of Human Ecology at the University of Alberta, Edmonton, Alberta, Canada. My study is about how Ugandan families affected by HIV/AIDS are coping with the impact of HIV/AIDS. I'm specifically interested in how widows who have certain resources, such as an education and a job and, who are heading their families, are coping after losing their husband/partner because of AIDS.

I've chosen to talk to you because you are experiencing this situation. I wonder if you might talk to me in a private interview setting. The interview will be an informal conversation where I will ask you some questions about how you and your family are managing and moving on with your lives. If you agree to participate in my study, any information you share with me will be used only by me and, possibly, by my supervisors in Canada. Your name and your personal information will remain secured with me and will never appear on any written materials or oral presentations resulting from this study. Most importantly, to make sure that you and your family won't be identified as people affected by HIV/AIDS, you are asked to pick the place where the interview can be conducted.

Also, if you agree to participate in my study and to be interviewed, I have an information sheet and a consent form that are written in English. I will give the information sheet and the consent form to you to read, or they can also be read to you if you request, in order for you to have a better understanding of my study and why I am doing it. I will give you these papers before the interview, so you will have enough time to read them or to request to have them read to you by me. You will also have enough time to ask me questions about anything that is not clear in the information sheet or consent form.

I will very much appreciate your agreement to participate in this study. I hope that the information you will share with me will provide a better understanding of the situation of families affected by HIV/AIDS, their day-to-day lives, and their methods of dealing with the impact of this disease. I hope that the results of this study can be used in the future by those working in the area of HIV/AIDS so that they can better plan for how to support families affected by this disease.

Now, I need to ask you this question: will you agree to participate in my study?

If you agree to participate in an interview, I may need to contact you again for a follow-up interview to further discuss how you and your family are dealing with the impact of HIV/AIDS.

APPENDIX B: INFORMATION SHEET

Appendix B: Information Sheet

Moving on: Ugandan Families and HIV/AIDS

Purpose:

HIV/AIDS affects the health and well-being of the person with the disease and other people related to and close to the affected person, such as family members. HIV/AIDS-affected families headed by widows are a growing population in sub-Saharan African countries like in Uganda, but life must go on for families who have lost the woman's husband/partner because of this disease. This study aims to understand how families headed by women are coping after losing their partner because of AIDS. What I will learn in this study will potentially be used to help create effective support for families affected by HIV/AIDS, particularly for affected families headed by women who are caring for children.

Approval by Authorities:

The University of Alberta in Canada and also the local authorities in Kampala, Uganda, represented by the Uganda National Council of Science and Technology, have given me permission to ask you to talk to me for the purpose of this study.

Methods:

I am asking you to participate in a maximum 90-minute informal, private interview with me. I will ask you some questions regarding your daily life and how you are coping and caring for your family since the death of your husband/partner. I am interested in your experience with this situation. Therefore, I would like you to share your story with me by using your own words. There are no right or wrong answers to the interview's questions. The interview will be tape-recorded and later typed out in the form of transcripts.

Confidentiality:

I am aware that people affected by HIV/AIDS may wish to remain anonymous. To protect your privacy, we can meet at your home or another location if you like. I will not disclose to anyone else anything that you tell me during the interviews. Your information will be used mainly by me and will be shared with my supervisory committee in Canada. Your name will not appear in any of my final reports, my dissertation, or any future publications and presentations related to this study's findings and will be replaced by pseudonyms to ensure your anonymity. However, anonymous quotations from your answers during the interview may be used in reports, publications and presentations related to this study to give credibility to the point I am discussing.

The tape-recorded and typed-out copies of the interview will be stored in a secure place while I am in Uganda and in a secure locked cabinet when I am back in Canada. The taped and typed-out interviews will be accessible only to me, the researcher. These materials may be made available to my supervisory committee in Canada, who may request to listen to the tapes and to read the typed-out interviews, mainly during the data-analysis phase of this study. All taped-records and typed copies of interviews will be completely destroyed after five years from the end of this study. I will do everything I can to ensure that your identity and the identity of your children and family members will remain anonymous.

Benefits and Risks:

Your participation in this study will not provide you with an immediate or direct benefit. However, I hope that the information I will gather from you and from other participants in this study will help in providing a better understanding of how families affected by HIV/AIDS are coping with the impact of this disease. This information may help professionals concerned with the impact HIV/AIDS is having on families to design better programs and improve services to support families living in this situation.

Participating in this study may provoke some sad memories during the interviews. Therefore, I have with me a list of support groups in your local areas or in the nearest vicinity so you can go to get some help and support if you think you need them. You will not be paid for your participation in this study, but you will be paid for transportation costs if you have to travel to reach the site of the interview.

Use of Information:

The information collected during the interviews may be used in different ways. It will be used for my PhD dissertation about how HIV/AIDS-affected families are coping with the long-term impact of this disease.

The final results of this study will be sent to NGOs, international agencies and governments departments that are concerned about the impact of HIV/AIDS on people in Uganda in particular and sub-Saharan Africa in general. The study's aim is to inform these bodies about this study's recommendations and the lessons learned from this study so that they can adopt the recommendations to effectively support families affected by HIV/AIDS. The interview data and this study's results are likely to be included in future research, publications and presentations.

If you would like to know about the results of this study, please indicate so on the consent form, which will be given to you to sign before the beginning of the interview. Please indicate how you would like a summary of this study's results to be sent to you and provide the necessary information, such as your mailing address, that will facilitate the delivery of this summary to you.

Withdrawal from the Study:

Your participation in this study is entirely voluntarily, and you are free to decline to participate in this study, to not answer any of the questions asked, and to withdraw from the study at any time.

Informed Consent:

If you agree to participate in the interview, you will be asked to read and sign a consent form before the interview begins. You will also be given a copy of this form to keep for future reference.

Contact Information:

Questions about this study may be directed to

Insaf Hag-Mousa, (The researcher)
Ph D. Candidate
Plot 22, Ntinda, 11 Road,
P.O. Box 88, Ntinda, Uganda
Ph.: (256) (0) 78696468 (Kampala)

Dr. Norah Keating, Professor, (PhD advisor)
Department of Human Ecology
3-22 Human Ecology Building
Univeristy of- Alberta, Edmonton, Alberta, Canada,
T6G 2N1
Ph.: (780) 492-4191

Dr. Walter Kipp, Professor, (PhD Advisor)
Faculty of Medicine and Dentistry
13-127 Clinical Sciences Building,
University of Alberta, Edmonton, Alberta, Canada,
T6G 2G3
Ph.: (780) 492-0364

APPENDIX C: CONSENT FORMS

Appendix C-1: Consent Form for Interviews with Widows

Moving on: Ugandan Families and HIV/AIDS

Investigator: Insaf Hag-Mousa, MD., MSc., PhD Candidate, Ph.: (256) (0) 78696468 (Kampala)

Supervisors:

Dr. Norah Keating, Professor, Department of Human Ecology, University of Alberta.

Dr. Walter Kipp, Professor, Department of Public Health Sciences, University of Alberta.

Consent to Participate:

Please circle your answers to the following questions:

Do you understand that you have been asked to take part in a research study?	Yes	No
Have you received and read a copy of the attached information sheet describing this study?	Yes	No
Do you understand the benefits and risks that may be involved in taking part in this study?	Yes	No
Have you had an opportunity to ask the researcher questions and to discuss issues of concern to you related to this study?	Yes	No
Has confidentiality been explained to you?	Yes	No
Are you satisfied with how your information will be kept confidential?	Yes	No
Do you agree to be tape-recorded during the interview?	Yes	No
Do you understand who will be able to listen to the recorded tapes and who may read the typed-out interviews?	Yes	No
Do you understand how the information collected in this study will be used?	Yes	No
Do you agree to the use of the information you will provide in this study in future research, publications, reports, and presentations?	Yes	No

Do you agree to be contacted in the future by the researcher for a brief follow-up interview to complete the information needed for this study? Yes No

I agree to take part in this study. Yes No

____________________ __________ ____________________
Participant Signature Date Witness

____________________ ____________________
Printed Name Printed Name

Would you like to receive a summary report of the results of this study after it is completed? Yes No

If your answer is yes, a summary of this study's results will be sent to you upon its completion. Please provide your mailing address information below:

Full Name:
Street address:
City:
Postal Code:

Appendix C-2: Consent Form for Widows
(to interview a child under or over 18 years)

Moving on: Ugandan Families and HIV/AIDS

Investigator: Insaf Hag-Mousa, MD., MSc., PhD. Candidate, Ph.: (256) (0) 78696468 (Kampala)

Supervisors:

Dr. Norah Keating, Professor, Department of Human Ecology, University of Alberta, Edmonton, Canada.

Dr. Walter Kipp, Professor, Department of Public Health Sciences, University of Alberta, Edmonton, Canada.

Widow's consent to her child's participation in the study:
Please circle your answer to the following question

Do you consent for your child (child's name _____________) to participate and be interviewed for this study?	Yes	No

_______________________ Widow Signature

____________ Date

_______________________ Witness

_______________________ Printed Name

_______________________ Printed Name

Appendix C-3: Consent Form for an Adult Interview

(18 years old and over)

Moving on: Ugandan Families and HIV/AIDS

Investigator: Insaf Hag-Mousa, MD., MSc., PhD. Candidate, Ph.: (256) (0) 78696468 (Kampala)

Supervisors:

Dr. Norah Keating, Professor, Department of Human Ecology, University of Alberta, Edmonton, Canada.

Dr. Walter Kipp, Professor, Department of Public Health Sciences, University of Alberta, Edmonton, Canada.

Consent to Participate:

Please circle your answers to the following questions:

Do you understand that you have been asked to take part in a research study?	Yes	No
Have you received and read a copy of the attached information sheet describing this study?	Yes	No
Do you understand the benefits and risks that may be involved in taking part in this study?	Yes	No
Have you had an opportunity to ask the researcher questions and to discuss issues of concern to you related to this study?	Yes	No
Has confidentiality been explained to you?	Yes	No
Are you satisfied with how your information will be kept confidential?	Yes	No
Do you agree to be tape-recorded during the interview?	Yes	No
Do you understand who will be able to listen to the recorded tapes and to read the typed-out interviews?	Yes	No
Do you understand how the information collected in this study will be used?	Yes	No

Do you agree to the use of the information you provide in this study in future research, publications, reports, and presentations?	Yes	No
Do you agree to be contacted in the future by the researcher for a brief follow-up interview to complete the information needed for this study?	Yes	No
I agree to take part in this study	Yes	No

Participant Signature Date Witness

Printed Name Printed Name

Would you like to receive a summary report of the results of this study after it is completed?	Yes	No

If your answer is yes, a summary of this study's results will be sent to you upon its completion. Please provide your mailing address information below:

Full Name:
Street address:
City:
Postal Code:

Appendix C-4: Consent Form for an Interview with a Young Child (Less than 18 years old)

Moving on: Ugandan Families and HIV/AIDS

Hi! My name is Insaf Hag-Mousa, and I am a researcher from the University of Alberta in Canada. I am doing a study trying to understand the situation of Ugandan families affected by HIV/AIDS and how they are coping with this disease. Therefore, I would like to ask you few questions about how you and your family are doing in this situation. The information you will share with me will help me to better understand your and your family's current situation. By the end of my study, I hope I will be able to find something that may help you, your family, and other families like yours to have a better life in the future.

I have talked to your mother and asked for her permission to let me talk to you. Your mother agreed to let me talk to you, but I still would like to ask you if you do not mind if I talk to you for few minutes. Please, feel free to refuse to participate in my study, to not answer any of my questions, or to stop talking to me at any time during our conversation. You will not have to explain your decision to me at all. If you decide not to talk to me, I promise you that your decision will not harm you in any way and that no one will know about it. If you agree to talk to me, I will not tell anybody about what you tell me, and I will never mention your name if I happen to use some of the information you will share with me. Your participation in my study will be highly appreciated, and I thank you for considering to allow me to discuss my study with you.

Do you understand what I am asking you for? Yes No

Do you agree to talk to me and participate in my study? Yes No

____________________ ____________ ____________________

Participant Signature Date Witness

____________________ ____________________

Printed Name Printed Name

APPENDIX D: DEMOGRAPHIC INFORMATION SHEET FOR WIDOWS

Appendix D: Demographic and Health Information Sheet for Widows

Moving on: Ugandan Families and HIV/AIDS

The following information needs to be collected to be used with the analysis of the interview data. Please fill out the following information or check the appropriate response.

Date: ________________ Participant ID No. ___________

Time started ______________ Time ended ______________

What is your full name?

____

Your address ______________________ Phone number _____________

Your age: ____

Your highest level of formal education:

___ Primary (elementary and/or junior high)
___ Secondary
___ Post-secondary
___ Graduate
___ Other ________________

Your current marital status:

___ Married/Common-law
___ Single
___ Divorced
___ Widowed

What is your HIV status?

Positive: _______ Negative: _______

If positive, for how long? ______________

Are you on ARVs? ___ Yes ___ No

If yes, for how long? _________

What was the relationship of the deceased AIDS male in the family to you?

___ Husband
___ Partner
___ Other (Specify)

For how long has your husband/partner been dead because of AIDS?

____

How many children do you have? (Indicate number of daughter and sons)

Daughters____ Ages __________ their HIV status _________ On ARVs ________

Sons _____ Ages __________ their HIV status _______ On ARVs _________

What type of living arrangement do you and your family members currently have?

___ Self-owned house
___ Private household
___ Rented home

___ Live with relatives
___ Other (specify) _____________

Who is living with you in your home and what is their relationship to you?

____
____
____
____

Who was the main breadwinner of the family before your husband/partner died? (Note: you may check more than one answer)

___ Husband/partner
___ Myself (the wife/partner)
___ Others (specify) _________________

Who is the main breadwinner of your family now?

___ Myself (the wife/partner)

___ Others (Specify)

Were you ever employed?

___ Yes

___ No

If yes, what kind of employment were you in?

___ Paid job e.g., Formal __________ For how long? _________

Informal __________ For how long? _________

___ Unpaid Job (specify) _______________ For how long? _________

Are you currently working/employed?

___ Yes

___ No

If yes, what kind of paid employment are you in now?

___ Formal Paid Job (Specify) ____________ For how long? _______

___ Informal Job (Specify) ____________ For how long? _______

What is your income? _________________

Did you have any savings/assets when your husband/partner died?

____ Yes ____ No

If yes, please specify the kind of assets you had (Money, land, etc.).

____

Do you have savings/assets now?

____ Yes ____ No

If yes, please specify the kind of assets you have? (Money, land, etc.).

____

____

How would you classify your family's socioeconomic class?

Low income _______

Middle income _______

High Income _______

APPENDIX E: INTERVIEW GUIDES

Appendix E-1: The Interviews' Guiding Questions

Questions to the Widows

First Interview

Introduction

Dear participant. In order for me to understand how you and your family are dealing with the impact of HIV/AIDS, I need to start by discussing what your daily life is like these days. You can help me by describing in detail your day-to-day life. I am interested in learning about what do you do every day, for I want to understand what your days are like. Could you begin by telling me what you did yesterday?

1. Please tell me how your day was yesterday.
    Probe: What did you do from the time you got up yesterday morning until the time you went to bed at night?
    Who did you see? What did you do? What did your children do?
    Was anything different about yesterday than other days of your life?
    What do you usually look forward to in your day?
    What are the difficult aspects of your day?

2. How are you and your family doing?
    Probe: How are you and your family managing your daily lives?
    What are you and your family doing to manage?
    What and/or who is helping you manage?
    What are the challenges you and your family are facing?

3. Do you have relatives?
    Probe: If yes, who are they?
    Where do they live?
    How is your relationship with them?
    Do you see them and if yes, how often?

Are they helping you and your family in any way?

If yes, what are they doing to help you and your family?

If no, why do you think your relatives are not helping you and your family?

After your husband's death, did your relatives help you and your family?

If yes, what did they do to help you?

If no, why do you think your relatives did not help you and your family after the death of your husband?

4. Do you have friends?

Probe: Do you see them?

How often?

How is your relationship with them?

Are they helping you and your family?

If yes, what are they doing to help you and your family?

If no, why do you think your friends are not helping you and your family?

After your husband's death, did your friends help you and your family?

If yes, what did they do to help you?

If no, why do you think friends did not help you and your family after the death of your husband?

5. Who is the person who has been most helpful to you in dealing with your situation, whether this person is a friend, relative, neighbor, co-worker, or anybody else?

Probe: What did this person do to help you and your family?

6. Do you have a job?

Probe: If yes, where do you work?

How long have you been working?

Why do you work, particularly in your situation?

7. Please tell me about how you are managing to support your family financially.

Probe: What are your sources of income?

Do you have enough income to support yourself and your children?

Do you have adequate income for food, clothing, education, needed medications or other health care expenses and other necessary living expenses?

Do you have any discretionary income for things like entertainment?

Has your income changed since the death of your husband/partner?

If yes, how did it change?

How is this change affecting you and your family?

How are you dealing with this change?

Note: At the end of the first interview, the researcher will thank the interviewee for participating in this first round of interviews. The researcher will then ask the interviewee if she is willing to schedule another appointment in order to discuss in detail how she and her family are doing and how they are moving on with their lives.

Appendix E-2: The Interview-Guiding Questions

Follow-up Interview with the Widows

Second Interview

Introduction

Dear participant. Thank you for agreeing to participate in a follow-up interview. In this interview, I am interested in asking you questions related to how you and your family are managing your lives and dealing with the issues resulting from you and your family being affected by HIV/AIDS, particularly after losing your partner/husband because of AIDS.

1. How has your family managed since the loss of your husband/partner?

   Probe: What are the difficult things/issues you have to deal with?

   How are you and your family, particularly the children, dealing with these issues?

   Describe to me what you and your family members are doing to deal with these difficult things.

2. Has anyone been helping you and your family in dealing with these difficult issues?

   Probe: If yes, who has been helping you to manage and deal with the difficulties you and your family have been experiencing?

   What has this person(s) been doing to help you and your family cope?

   What else, if anything, has helped you and your family to manage, and how has it helped you?

3. What helped you to manage and deal with the issues you and your family are facing?

   Probe: What do you have as a person that may have helped you to manage your life and your family's life (referring to personal resources)?

   How are these things that you have helping you and your family?

4. Did your education help you and your family to manage your situation?

Probe: If yes, how did your education help you manage? I.e., in what way?

5. Did your employment help you and your family manage?

   Probe: If yes, how is it helping you and your family manage? I.e., in what way?

6. What has been most difficult for you and your family to deal with?

   Probe: Why?
   How?

7. What has been most helpful to you and your family in moving on with your lives?

   Probe: Why?
   How?

8. What do you think you and your family still need in order for you to do better?

   Probe: What other things do you think you and your family still need to have or acquire to better manage your situation?
   What other ways or means of dealing with the situation do you and your family still need to develop/adopt so you can do better?

9. What do you wish for yourself and your family?

10. How do you see your future and the future of your family?

    Probe: Are you preparing for the future?
    If yes, when did you start preparing for the future?
    How are you preparing for the future?
    Why are you preparing for the future?
    What do you need to be able to prepare for the future?

11. Do you think there is hope for you and your family?

    Probe: If yes, why do you think so?

Appendix E-3: The Interview-Guiding Questions

Questions to the Children
(Under and above 18 years)

1. How are you doing?

    Probe: Do you go to school?

        If yes, which grade are you in?

        How are you doing in school?

2. How is the situation in your home?

3. Do you help at home?

    Probe: If yes, in what way? What do you do to help?

        If no, why you are not able to help?

4. What has been the most difficult thing for you and your family to deal with after your father's death?

    Probe: Why do you think so?

5. Who has been helping you and your family to manage?

    Probe: In what way? I.e., What did this person do to help you and your family?

6. What do you think you and your family still need to have so all of you can have a better life?

    Probe: Why do you think so?

        How do you think you and your family can get what you need so you can do better?

7. How do you feel about your future and the future of your family?

    Probe: Why do you feel so?

Appendix E-4: The Interview-Guiding Questions

Question to Other Participants
(Adult Family and Non-Family Members)

1. What is your relationship to the widow (mention widow's name __________) and her children?

2. Have you been involved with this family?
   Probe: If yes, when did you become involved?
   How did you become involved?
   Why did you decide to become involved?

3. Did you do anything for this family?
   Probe: If yes, how and what have you done to help?
   If no, why haven't you helped?

4. What do you have as a person to offer to this family to help its members move on with their lives?

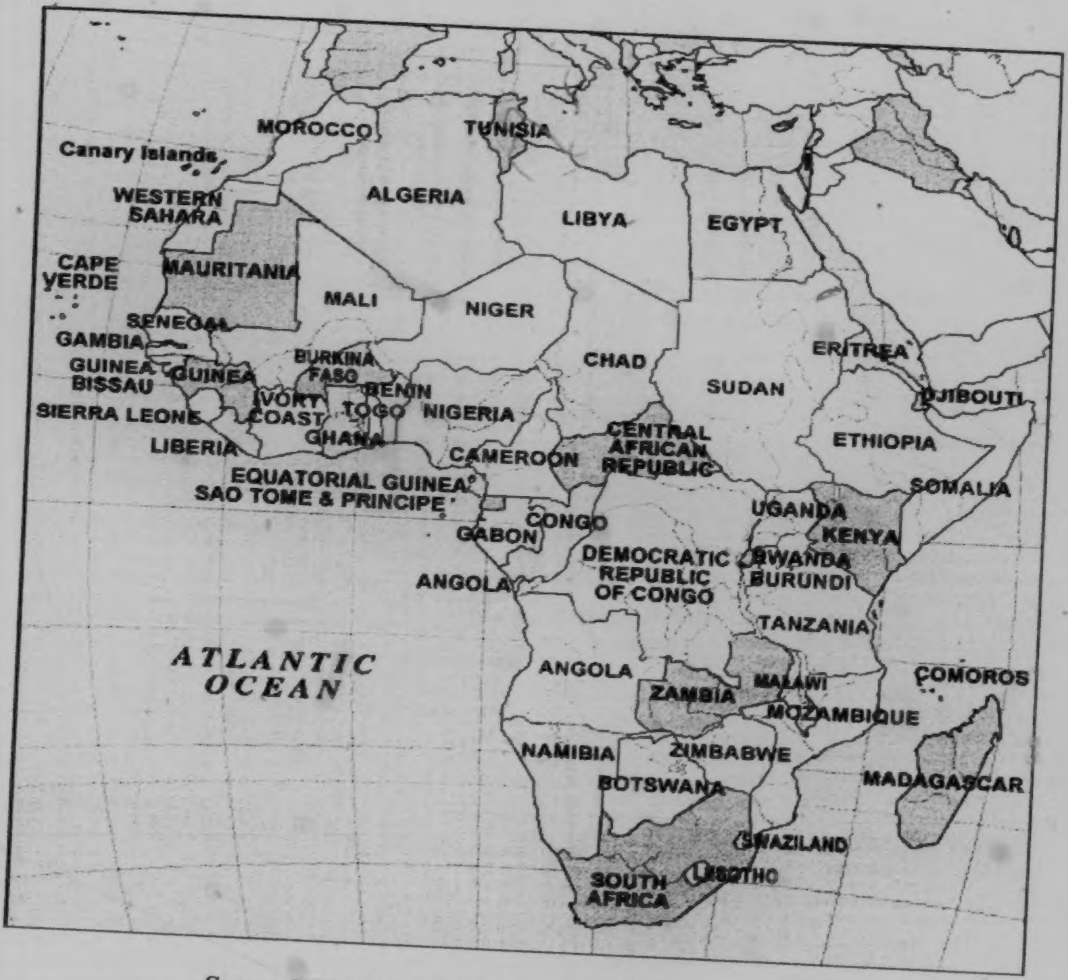
5. What has been difficult for you to handle in your effort to help this family?
   Probe: Why do you think so?

6. What do you think has been helpful in helping this family deal with its situation?
   Probe: Why do you think so?

7. What do you think this family still needs to have that would help its members do better?
   Probe: Why do you think so?
   How do you think this family can get what it needs?

8. How do you see this family's future?
   Probe: Why do you think so?

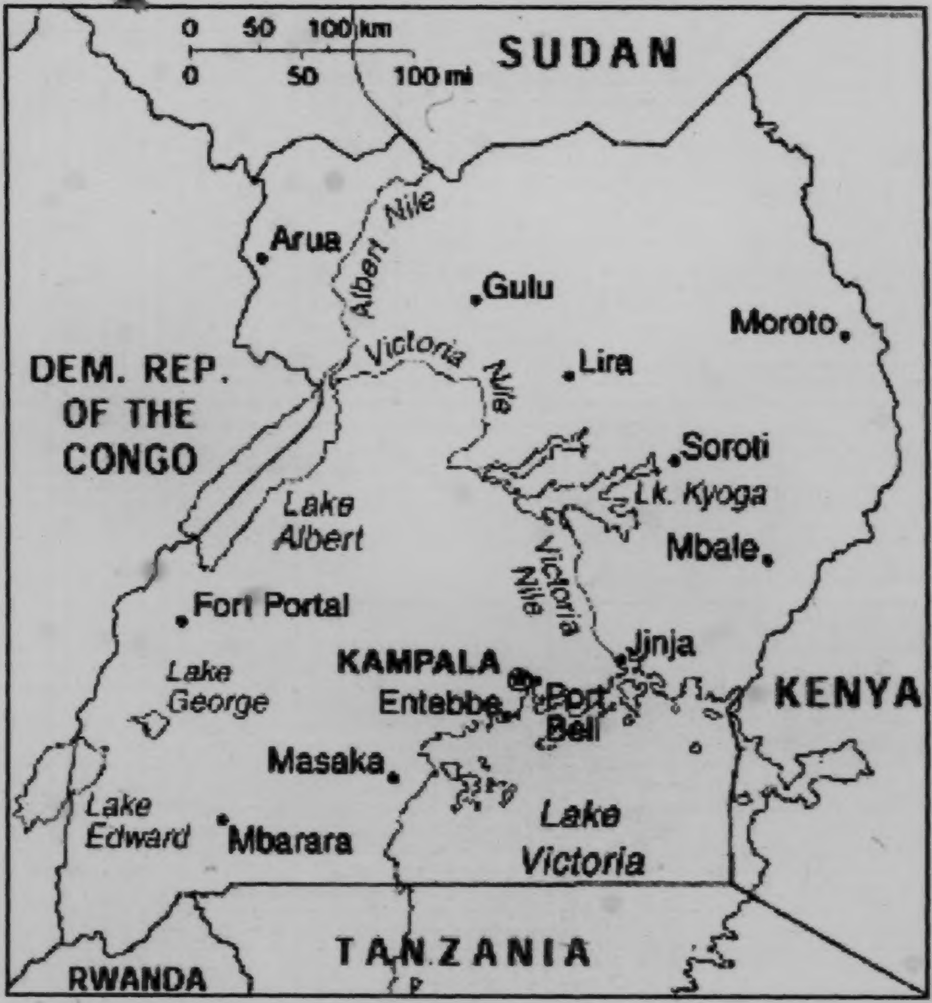
APPENDIX F: UGANDA's LOCATION IN AFRICA


MOROCCO
TUNISIA
Canary Islands
WESTERN SAHARA
ALGERIA
LIBYA
EGYPT
CAPE VERDE
MAURITANIA
MALI
NIGER
SENEGAL
GAMBIA
CHAD
ERITREA
GUINEA BISSAU
GUINEA
BURKINA FASO
BENIN
SUDAN
DJIBOUTI
SIERRA LEONE
IVORY COAST
TOGO
NIGERIA
LIBERIA
GHANA
CENTRAL AFRICAN REPUBLIC
ETHIOPIA
CAMEROON
EQUATORIAL GUINEA
SAO TOME & PRINCIPE
SOMALIA
UGANDA
CONGO
KENYA
GABON
DEMOCRATIC REPUBLIC OF CONGO
RWANDA
BURUNDI
ANGOLA
TANZANIA
ATLANTIC OCEAN
ANGOLA
COMOROS
MALAWI
ZAMBIA
MOZAMBIQUE
NAMIBIA
ZIMBABWE
MADAGASCAR
BOTSWANA
SWAZILAND
LESOTHO
SOUTH AFRICA

Source WorldAtlas.Com. Retrieved November 14, 2007, from

http://www.world-atlas.us/africa-map.gif

APPENDIX G: MAP of UGANDA


0 50 100 km
0 50 100 mi
SUDAN
Albert Nile
Arua
Gulu
Moroto
Victoria Nile
Lira
DEM. REP. OF THE CONGO
Soroti
Lk. Kyoga
Lake Albert
Mbale
Victoria Nile
Fort Portal
Jinja
Lake George
KAMPALA
Entebbe
Port Bell
KENYA
Masaka
Lake Edward
Mbarara
Lake Victoria
TANZANIA
RWANDA

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